DOCUMENT RESUME

ED 300 990	EC 211 286
AUTHOR TITLE	Schrag, Emily Sensitivities, Skills, and Services: Mental Health Roles in the Implementation of Part H of PL 99-457 the Education of the Handicapped Act Amendments of
INSTITUTION	1986. An Issue Paper. Georgetown Univ. Child Development Center, Washington, DC.; National Center for Clinical Infant Programs, Washington, DC.
SPONS AGENCY	National Inst. of Mental Health (DHHS), Rockville, Md.
PUB DATE	88
NOTE	22p.; Prepared for the Child and Adolescent System Program.
PUB TYPE	Information Analyses (070) Reports - Descriptive (141)
EDRS PRICE	MF01/PC01 Plus Postage.
DESCRIPTORS	Compliance (Legal); Delivery Systems; *Emotional Disturbances; *Federal Legislation; Infants; *Mental Health Programs; Professional Services; Program Development; Role Perception; Toddlers
IDENTIFIERS	*Education of the Handicapped Act Amendments 1986

#### ABSTRACT

The report analyzes roles of mental health professionals in implementing Public Law 99-457, the Education of the Handicapped Amendments of 1986, which established the Cuild and Adolescent Service System Program (CASSP). A December, 1987, conference of administrators, clinicians, policymakers, and parent representatives from federal, state, and community programs considered the mental health needs of children from birth through age 2. This document reports their discussions of: (1) the population of infants and toddlers needing mental health attention and services through P.L. 99-457 and other programs; (2) elements of a continuum of mental health services; and (3) possible roles and responsibilities for mental health professionals and agencies serving infants, toddlers, and their families within the framework of P.L. 99-457. Contributions of mental health professionals can include their sensitivities to emotional and psychosocial issues; their skills in screening, assessment, diagnosis, intervention, and program evaluation; and their current services in the private sector, voluntary agencies, community mental health centers, school systems, and state mental health agencies. Questions to guide program planning are offered as is a listing of 11 resource organizations. Appended are a summary of P.L. 99-457, a list of the meeting's participants, a list of state Part H lead agency contacts, and the CASSP annual report. (DB)

*****	******	**********	* * * * * * * * * * *	* * * * * * * * * * * * * * * * * * * *	******
*	Reproductions	supplied by	EDRS are	the best that can be	made *
*		from the	original	document.	*
****	******	******	*******	* * * * * * * * * * * * * * * * * * * *	*****



U.S. DEPARTMEN' OF EDUCATION Office of Educational Resourch and Improvement EDUCADONAL RESOURCES INFORMATION CENTER (ERIC)

This document has been reproduced as received from the person or organization originating it

D Minor changes have been made to improve reproduction quality

 Points of view or opinions stated in this document do not necessarily represent official OERI position or policy

MATERIAL HAS BEEN GRANTED BY

"PERMISSION TO REPRODUCE THIS

UCATIONAL RESOURCES

SENSITIVITIES, SKILLS, AND SERVICES: MENTAL HEALTH ROLES IN THE IMPLEMENTATION OF PART H OF FL 99-457 THE EDUCATION OF THE HANDICAPPED ACT AMENDMENTS OF 1986

> Prepared by: Emily Schrag National Center for Clinical Infant Programs

> > Project Coordinator:

Roxane Kaufmann CASSP TA Center Georgetown University Child Development Center



# TABLE OF CONTENTS

Introduction	3
Population to Be Served	3
Continuum of Care Model	5
Mental Health Roles and Responsibilities Under P.L. 99-457	7
Conclusion	9
Next Steps	9
Resources	10
Appendices:	
A. Summary of P.L. 99-457	12
B. List of Meeting Participants	16
C. List of Part H Lead Agency Contacts	17
D. Child and Adolescent Service System Program (CASSP)	



# INTRODUCTION

Among the marvels of human growth in the first months and years of life is the way in which even the youngest baby develops and integrates new abilities in many domains at once. In this process, the emotional growth, emergence of self-confidence, specific patterns of attachment to caregivers, and the increase of competency in human relationships of the infant or toddler are as crucial to overall development as are physical growth or motor skills. Indeed, the mental and emotional health of the very young child can be seen as the necessary foundation for all further development.

Emotional growth and well-being are particularly critical issues for infants and toddlers who face the challenges of disabilities or serious illness. If young children feel loved and valued by those around them and take pleasure in their own achievements, they can often make the most of their abilities, whatever the difficulties they confront. However, when young children with motor delays, sensory-processing problems, or other handicapping conditions lack appropriate understanding and support, mental health problems are likely to develop.

It is important to remember that the development of the infant and toddler is intimately connected to the child's experience in the family. A warm, consistent, and pleasurable relationship between the baby and the parents which begins at birth nurtures and encourages the competence of the child and of the child's parents. Illness or impairment can make it difficult for a baby to respond or to reach out to his parents; in their grief and bewilderment, parents may also become less responsive. Parents who are abusive, overwhelmed, or insensitive can discourage a young child from seeking involvement in human relationships.

The fate of the infant and that of his family are increasingly linked to the wider community. Every family with young children depends on a wide range of informal and institutional supports in order to meet the demands of contemporary living. When families have an infant or toddler with special health or developmental needs, they require a wide range of skilled, specialized family-centered services, so that all of the family members can cope with the challenges that confront them and can assist in fully developing the child's talents.

Comprehensive, integrated service systems that can attend to the multiple developmental needs of infants, toddlers and their families within their own communities have seldom existed in this country. The enactment of P.L. 99-457, the Education of the Handicapped Act Amendments of 1986, provides an opportunity not only to change service systems, but also to change the behaviors, attitudes, and training approaches that underlie them. The goal is to integrate multiple and diverse, formal and informal supports and services in ways that recognize the strengths of families and respond to their daily needs.

Just as emotional and mental health are critical to the overall development of children and families, so are the insights from mental health disciplines, the skills of mental health professionals, and the resources of mental health agencies crucial to the effective implementation of P.L. 99-457. In an effort to delineate the opportunities and challenges involved in the fruitful collaboration among mental health, health, education, social service and other agencies on behalf of the infants, toddlers and families who will be affected by Part H of the new legislation, the Child and Adolescent Service System Program (CASSP) of the National Institute of Mental Health called together administrators, clinicians, policymakers and parent representatives from a variety of federal, state, and community programs. Their expertise in understanding and addressing the mental health needs of children from birth through two years of age, and the mental health needs of their families are reflected in the following discussion of:

- the population of infants and toddlers who should receive mental health attention and services through P.L. 99-457 and other programs;
- elements of a continuum of mental health services;
- possible roles and responsibilities for mental health professionals and agencies serving infants, toddlers and their families within the framework of P.L. 99-457.

It is hoped that this discussion will be useful to a broad range of practitioners who wor' with infants, toddlers, and their families; to parents; to federal and state administrators of health, mental health, education, and social service agencies; and to program developers and staff of community agencies. Creative collaboration among all of these groups is essential in order to address appropriately and successfully the mental health needs of very young children and their families.

## THE POPULATION TO BE SERVED

P.L. 99-457 states that "handicapped infants and toddlers" are

... individuals from birth to age 2, inclusive, who need carly intervention services because they: (A) are experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures in one or more of the following areas: cogni-



tive development, physical development, language and speech development, psychosocial development, or self-help skills, or (B) have a diagnosed physical or mental condition which has a high probability of resulting in developmental delay. Such term may also include, at a State's discretion, individuals from birth to age 2, inclusive, who are at risk of having substantial developmental delays if early intervention services are not provided."

It is the responsibility of each state to define the term "developmentally delayed" as it will be used by that state to carry out programs under Part H, the section of the law that concerns infants and toddlers.

As planners, administrators, parents, practitioners, and advocates in any state consider the mental health needs of children from birth through two, and the mental health needs of their families, they will want to survey the whole range of human and material resources available in the state to meet these needs. They will need to remember that the development of the young child must be viewed in the context of the child's primary relationships, and the enhancement of these relationships must be a chief goal of any service program for infants, toddlers, and their families. The service system described in P.L. 99-457 is designed to complement, not to replace or recreate, a network of informal social supports, family resources, other preventive programs, and health, education and social services. To the extent that these supports and services strengthen the positive relationships between young children and their parents (who are usually the primary caregivers), they can have an important beneficial impact on the emotional well-being and growth of infants and toddlers with disabilities and their families.

The unique strengths and vulnerabilities of every child and family and the complexities of their relationships must always resist categorization. However, program developers may find it useful to think of three broad groups of children from birth through age two whose mental health needs may be effectively addressed through the service system described in P.L. 99-457. Again, it must be stressed that the wellbeing of the very young child is so connected to the well-being of his family that some service system planners prefer to think of the "child-and-family" as a single unit. Unfortunately, neither the current organization of health, education and social services in most states, nor the language of relevant federal and state legislation makes such an integrated vision easy to implement. It is one of the great strengths of P.L. 99-457 that Individualized Family Service Plans, the blueprints for service delivery, are designed to protect and enhance family relationships. Emphasis is placed on acknowledging and building upon family strengths. It is also recognized that a variety of stresses may reduce or even overwhelm a family's capacity to provide the physical protection, emotional nurturance,

or cognitive and social experience necessary to support the young child's development. Services must recognize and address the family's needs as well as those of the child.

## Infants and Toddlers With Diagnosed Handicapping Conditions; Infants and Toddlers Who Experience, or Are at Risk of Physical, Cognitive, or Sensory Developmental Delays

Whether they involve motor or sensory impairments, mental retardation, the sequelae of premature birth, or serious illness, the disabilities of very young children can represent a source of potential distress and difficulty in relationships which can impair the development of the child and the functioning of the family. The relationship between a child and his parents is usually affected by a disability or developmental delay, both directly and indirectly. A child's disability may literally interfere with normal routes of communication of pleasure and satisfaction; parents' feelings about the child's disability or delay will also powerfully affect the relationship. Children with disabilities may have difficulty in such basic areas as the capacity to relate to others, to control impulses, to experience positive self-esteem, to develop the ability to distinguish fantasy from reality, to develop the ability to focus attention, to concentrate, and to plan.

Supportive, proactive mental health services to these children, and their families, are needed to help them achieve their fullest potential and improve the quality of their human relationships. These services may make the difference between a family's ability to care for a child at home with the support of community services, or the need for institutional placement.

## Infants and Toddlers With Diagnosable Mental Health Disorders; Infants and Toddlers Who are Experiencing, or are at Risk for Delays in Psychosocial or Social/Emotional Development

Some children between birth and three years of age are already in serious difficulty emotionally, and are impaired in their daily functioning and relationships. While some of these children evidence "developmental delays," others do not. Even though our ability to diagnose mental and emotional disorders in young children has not kept pace with clinical understanding of the development of such problems, some diagnostic categories, such as failure to thrive, pervasive developmentai disorders, autism, and disorders of attachment, do exist for this age group. In other instances, mental and emotional damage is readily observable in infants and toddlers. The fearfulness and hypervigilance typical of the abused infant, for



example, look very much like the symptoms found in adults of post-traumatic stress or panic. Careful observation of infants and toddlers as they interact with their environment and caregivers is one of the most useful tools that clinicians and parents have, since many mental health problems cannot be diagnosed in any other way.

When one considers *delays* in psychosocial development, in contrast to diagnosable mental health *disorders*, one may find it useful to think of young children who have reached 50% or less of their expected age level of functional development as experiencing a substantial psychosocial delay.

Some expected psychosocial milestones for infants and toddlers include:

- by 4 months—evidence of pleasurable, intimate patterns of relating between infant and parents
- by 10 months—purposeful vatterns of communicating needs
- by 18 months—orchestrated, complex patterns of social behavior, which includes social imitation, some control of impulses, and interest in other children
- by 30 months—evidence of ability to symbolize emotion and behavior through interactive pretend play and the functional use of language
- by 42 months—establishment of basic personality functions, which includes reality testing, impulse control, complex relationship patterns (including both sharing and self-protection), positive self-esteem, and the ability to concentrate and to plan.

Substantial delays in psychosocial development in young children are likely to become more severe and increasingly pervasive unless appropriate intervention is forthcoming.

## Infants and Toddlers in Multi-Risk Families

Significant family stress will affect the experience of any infant or toddler, with or without physical disabilities, developmental delays, mental or emotional disorders or evidence of delay in psychosocial development. Of greater concern than any single source of stress is the situation in which multiple stresses impinge upon a child or family. When a number of stresses such as marital discord, family violence, mental illness, substance abuse, extreme economic deprivation, single and/or teenage parenthood exist in any one family, there is a high probability that children will experience cognitive and emotional delays by age four. Thus, although a given infant or toddler may not show signs of psychosocial delay or mental/ emotional disorder at the time the child is observed, if the child's family is multiply stressed, early intervention to support the family and protect the child's development is indicated to prevent substantial delay.

# A CONTINUUM OF CARE MODEL

Before the attempt is made to discuss possible roles for mental health professionals and agencies within the framework created by Part H of P.L. 99-457, it may be worthwhile to imagine how mental health services for very young children and their families might ideally be organized within a state or community. One way of conceptualizing a continuum of mental health care for young children and neir families is to envision five levels of service. These might be designated as mental health promotion, preventive/proactive care, supportive care, supplemental care, and substitute care.

Mental Health Promotion. Promotion has a very broad scope and can be considered "good for" everyone. Examples include parenting and family life education throughout the elementary and secondary school years, as well as for adults; the integration of infant mental health concepts in parent preparation classes and in guidance offered by primary health care providers; encouragement of participation in naturallyoccurring social support networks; and multimedia educational campaigns which all contribute to community-wide mental health promotion.

**Preventive/Proactive Care.** Prevention measures are geared to populations considered to be at risk because of specific genetic or environmental factors. Preventive measures are made available to the whole "at risk group" before symptoms emerge rather than on a case-by-case treatment basis. Thus, in areas where natural support systems have eroded or failed to develop, agencies might organize family resource programs or train day care providers in the community to pay specific attention to the emotional growth and well-being of both young children and parents. Home visits to mothers of low birthweight premature infants born into multiproblem families, to provide concrete assistance and emotional support, would be another example of preventive care.

Supportive Care. As the term suggests, supportive care services are designed to increase the capacities of family members to foster and maintain the emotional well-being of their young children and of the family as a whole in the face of some specific challenge. For example, when a well-functioning couple is faced with the birth of a child with a disability, parent-to-parent support networks, education concerning the infant's special developmental and emotional needs, counseling for parents and other family members, and care coordination may all be important supports to the couple's own coping and caregiving abilities. When the family itself is seen as "at risk" for problems in adequate parenting, support of the family's strengths and assistance to family members in acquiring new skills to enhance the child's development are neces-



sary. Day care services that emphasize modeling and support for parents; home- and center-based programs involving parents and children together; group, couples, and individual counseling or psychotherapy; infant-parent psychotherapy; and the provision of assistance to meet concrete needs may be appropriate. Hospitals, pediatric clinics and day care centers can play an important role in identifying families that may profit from early supportive intervention. The importance of viewing the family unit as a whole is critical in the area of supportive or supplemental care.

Supplemental Care. For some young children and families, services that supplement the family's own efforts may be needed on a temporary, periodic or continuing basis in order to protect the child and family's emotional well-being and continued development. For example, developmental day care, provided to at risk and developmentally delayed toddlers in a homeless shelter, has been shown to result in rapid improvement in the children's abilities to socially interact with one another; but unless comparable support and treatment is simultaneously provided to their depressed mothers, these early gains are ultimately negated. Reliable respite care may do much to preserve the marriage of parents of a child with demanding special health care needs or difficult behavioral problems. A volunteer "family friend" may provide important opportunities for a satisfying relationship to both the young child and the single parent in, what would otherwise be, an isolated and overstressed family situation. A developmental day care program can provide appropriate stimulation to the toddler whose mentally retarded parents can give her love and physical care but cannot help her reach levels of cognitive and emotional integration that would be natural for her age. Day treatment programs and other forms of psychotherapy may serve the needs of both the emotionally disturbed parent and the developing infant or toddler.

Substitute Care. When the needs of child and parent cannot be met within the family and home environment, substitute care will be required. Short or long-term inpatient or residential care and foster care that includes specific attention to mental health needs are examples of substitute care services. The importance to children during the first three years of life of stable, nurturing relationships with a limited number of caring, sensitive adults cannot be overemphasized in planning and implementing substitute care services, which are the most restrictive options in a continuum of care and are only considered when other choices have been exhausted. Therefore, substitute care capacities should be developed that reduce multiple placements and maintain family involvement as clinically appropriate.

Any continuum of mental health care for young children and their families will depend for its effectiveness on several features that cut across all levels of service. These include:

- an ongoing commitment to the importance of mental health services by planning and funding authorities;
- a coordinated delivery system of primary and specialized services that is family-centered, community-based, and culturally sensitive, and that includes adequately funded outreach;
- appropriate training and technical assistance not only for mental health professionals but also for primary health care personnel, early intervention professionals, child care providers, parent educators and home visitors, and community volunteers;
- the ability of the service system to help families gain access to necessities for survival, which include adequate income, housing and basic health care;
- active participation of families in planning and implementing treatment plans, with homebased services to support and strengthen family capabilities;
- advocacy services for families.

# The Continuum of Care Model and P.L. 99-457

Although many excellent models of mental health promotion, prevention, outreach, support, and intensive treatment programs are available for infants, toddlers and their families in communities across the country, in no state or community does a truly comprehensive continuum of mental health services for this population currently exist.

Some of the barriers to a comprehensive, coordinated system of mental health services for children from birth through age two and their families are similar to those faced by most health, education and social service systems. Fragmentation of services, combined with inadequate resources for referral and coordination; restrictive eligibility criteria; the lack of common vocabulary among personnel of different disciplines and agencies; interdisciplinary mistrust; cultural insensitivity; service delivery mechanisms too inflexible to accommodate the schedules of working families; and inadequate funding are by no means unique to mental health service systems.

P.L. 99-457 was not designed to provide a full continuum of services to infants, toddlers and their families with mental health needs. The law does not, for example, address mental health promotion or preventive care directly, although its public awareness, child find and interagency coordination provisions may result in important side benefits in these areas. P.L. 99-457 does, however, provide many opportunities for professionals and agencies with expertise in infant mental health to contribute their unique sensi-



tivities, skills and services to address the emotional well-being of children and their families during the critical first three years of life.

## MENTAL HEALTH ROLES AND RESPONSIBILITIES UNDER P.L. 99-457

According to P.L. 99-457, a "statewide system of coordinated, comprehensive, multidisciplinary, interagency programs providing appropriate early intervention services to all handicapped infants and toddlers and their families" shall include 14 minimum components. While it is a basic assumption of this paper that mental health expertise and mental health professionals should be involved in all phases of the planning and implementation of the P.L. 99-457 system of services within a state, several of the 14 components offer especially important opportunities for mental health contributions.

Definition of "developmentally delayed." As discussed in the section on the population to be served, delays in psychosocial development must be accorded the same attention as delays in other areas of development; infants and toddlers with "diagnosed ...mental condition(s) which [have] a high probability of resulting in developmental delay" are also seen as needing early intervention services. Because the state of the art in diagnosing mental and emotional disorders in children under three is relatively poorly advanced, and because very real problems attend the "labeling" of young children, professionals with infant mental health expertise have a significant role to play in helping the state planning bodies decide which children who are experiencing, or who are at risk of, emotional and psychosocial problems can best be served through P.L. 99-457 and how to assure appropriate mental health services for other young children and families through other systems of care.

Multidisciplinary Evaluation. Professionals with expertise in child and family mental health diagnosis and treatment can help to assure that the required "timely, comprehensive multidisciplinary evaluation of the functioning of each handicapped infant and toddler...and the needs of the families to appropriately assist in the [child's] development" includes attention to psychosocial issues, takes place in a developmental context, and uses the family as the principal articulator of its own and the child's needs. Whether the mental health role in evaluation should be taken by a psychiatrist, by another mental health professional, or by a specially trained professional from another discipline will vary from one situation to another and from urban to rural systems.

Individualized Family Service Plan, Including Case Management Services. The written individualized family service plan (IFSP) provides the opportunity for parents and members of a multidisciplinary team to jointly identify the strengths and needs of the child and family, including a statement of "specific early intervention services necessary to meet the unique needs of the infant or toddler and the family, including the frequency, intensity, and the method of delivering service." It is important for planners to be aware that all services identified on the IFSP do not have to be paid for by the lead agency, but that new mechanisms for linkages, blended funding and other collaborative arrangements must be developed. Unfortunately, it is the exceptional community that is able currently to offer its infants, toddlers and their families even a few of the preventive, supportive, supplemental or substitute mental health services described above a part of a continuum of care for this population. Nevertheless, the articulation of needs and the process of conceptualizing an appropriate service plan in conjunction with the family enable that family and case manager to devise the most promising plan possible using the resources available. Individually and collectively, IFSPs also document unmet needs, providing a basis for future planning and advocacy.

Because the case manager or care coordinator is likely to be an important person in the life of the handicapped infant or toddler and his family, careful consideration should be given to the circumstances under which the case manager should be a mental health professional. A mental health professional may likely be an appropriate case manager when the child in question has a mental or emotional disorder as the primary diagnosis or when emotional development is significantly delayed. If the family's capacity to enhance the development of the infant or toddler is of primary concern, that professional who has the best relationship with the family, whatever her discipline, is likely to be the most effective coordinator of care.

Mental health professionals should be particularly sensitive to the provision in P.L. 99-457 for periodic reviews of individualized family service plans "at 6-month intervals (or more often where appropriate, based on infant and toddler and family needs)". Such reviews offer opportunities for parents and professionals to define and meet needs in some meaningful order and to assign the case management role to the professional "most immediately relevant" to child and family needs at a particular time.

**Comprehensive Child Find System.** It is in a "child find" system that a continuum of mental health care can begin, and here that state implementers of P.L. 99-457 may find it effective to adopt the prevention perspective found in good mental health programs. The more general and preventive a program, the less stigma is likely to be attached to it. In a child find



program, mental health professionals can serve as consultants to such natural "gatekeepers" as the providers of perinatal care, public health nurses, pediatricians, day care providers, family resource program personnel, and protective services staff. With appropriate training and back-up support, these individuals can not only identify infants, toddlers and families with mental health needs but, as trusted participants in ongoing relationships with parents, can often provide emotional support and guidance. Again, with collaborative planning they can design the integrated, multidisciplinary programs indicated by local assessment.

Professionals within the general mental health service system in a community or state can be particularly helpful in identifying the mental health needs of young children whose parents are in treatment for, or who have a history of, mental or emotional disorders or drug or alcohol dependency. These infants and toddlers may be at high risk for developmental problems, but unless sensitized to their needs and to the availability of services to support their development, professionals may tend to focus exclusively on the mental health problems of their parents.

Public Awareness Program. Increased public awareness of the importance of fostering and protecting confidence, self-esteem, and success in human relationships in the very youngest children will be needed before policymakers and funders give priority to necessary services. Like a child find program, a public awareness program that includes information on the emotional needs and development of infants, toddlers and their families should be positive and non-threatening. Media-based public awareness campaigns, information delivered through perinatal services, new parent newsletters, and parent resource centers with outreach programs can all include mental health content. Their message should be, "It is natural and responsible to ask for help in parenting," rather than, "Here are six signs that your baby may have an emotional disorder." Communications should be culturally appropriate and directed toward settings likely to be frequented by parents of young children. Recent research findings concerning infant mental health can be translated into messages that emphasize the importance of early nurturing and the centrality of a loving parent-child relationship in a healthy childhood.

**Central Resource Directory.** P.L. 99-457 requires that a central directory include "early intervention services, resources and experts available...and research and demonstration projects being conducted in the state." Mental health planners and mental health professionals should be involved in planning and producing such a directory so that mental health services, resources and experts will be included. Even though "systems" of mental health care for young children may not be well established, many states have organizations of multidisciplinary professionals who are knowledgeable and concerned about infant mental health; coalitions of family resource programs; excellent individual programs in hospital, university or community settings; and individual practitioners, researchers, educators and administrators in a wide range of agencies and institutions and in private practice who can provide invaluable consultation, training and technical assistance.

Personnel Development and Standards for Training. The kinds of family-centered, coordinated, community-based approaches envisioned by the framers of P.L. 99-457 require enormous changes in the behaviors and attitudes of professionals and paraprofessionals who work with infants, toddlers and their families. Virtually all front line practitioners will need knowledge and skills concerning: the physical, cognitive, motor, sensory, social and emotional development of infants and toddlers; forming and maintaining effective partnerships with parents; coordinating care for child and family; and functioning as a member of a multidisciplinary team. To be effective over the long term, practitioners also need manageable case loads, skilled supervision, peer support, in-service training to keep in touch with new knowledge, and opportunities for career development, including adequate salaries.

Because children from birth to age three and their parents face unique developmental challenges, special training is needed for effective mental health service to infants, toddlers and their families. Mental health professionals who are experienced in infant, toddler and family work, along with occupational therapists, physical therapists, pediatric nurses, developmental psychologists, special educators and pediatricians who have infant mental health training and experience, can be invaluable as trainers of health, mental health, education, and social service personnel at both the preservice and inservice level. They can also provide consultation about emotional problems in individual children and about ways to foster emotional growth within early intervention programs to front line practitioners and administrators in a host of service settings. The goal of training and consultation should be both the reinforcement of effective behavior on the part of primary care providers and natural helpers and the enhancement of their sensitivity to emotional aspects of development in the first years of life. At the same time, mental health professionals have much to learn about infancy from other professionals and from parents, and about the total range of resources for children and families in the community.



# CONCLUSION

P.L. 99-457 challenges practitioners, progam developers, administrators, advocates, educators and parents to take a fresh look at the strengths and needs of infants and toddlers who are experiencing, or who are at risk of developmental delay, and of their families, and to mobilize all available human and material resources to enhance their development. This is no easy task. And the funds, policy guidance and technical assistance that will be provided to states through P.L. 99-457 can be only a catalyst for change: major alterations must take place in funding patterns at the state level; in collaboration among community and state agencies; in partnerships with parents; in the structure and delivery of specific services; in personnel preparation; and in the beliefs, attitudes and levels of commitment of countless individuals in order for the promise of the legislation to be realized.

The opportunities offered by P.L. 99-457 to mental health professionals and agencies are purticularly significant. For the past two decades, findings from mental health and child development research have demonstrated both the tremendous importance of emotional and social development during the first three years of life and the vulnerability of the child to serious emotional damage during this period. Practitioners from a wide range of disciplines have devised strategies to translate research findings into effective prevention and intervention approaches designed to foster the healthy development of infants, toddlers and their families. Yet even though increased attention has been paid at the federal and state level in recent years to the mental health needs of seriously emotionally disturbed children, few resources have been directed specifically to children from birth through age two and their families. With P.L. 99-457's emphasis on collaboration and pooling of resources, it may now be possible for mental health expertise to reach and to benefit at least a significant proportion of the very young children and their families who need mental health services.

Contributions can be made at many levels:

- The sensitivities of mental health disciplines to emotional and psychosocial issues should inform the training of all front line practitioners who work with infants, toddlers and their families. Mental health insights can be equally useful in understanding the complex group processes that will be involved in policymaking to implement the law.
- The specific skills of mental health professionals in screening, assessment, diagnosis, intervention and program evaluation should be used to collaborate with other professionals and parents in direct clinical services in consultation, in pro-

gram development, and in training and technical assistance.

• The mental health *services* that currently exist in the private sector, in voluntary agencies, in community mental health centers, in school systems, and in state mental health agencies should be included in the family-centered, community-based, coordinated systems of care envisioned in P.L. 99-457. Representatives of state mental health agencies should serve on the state Interagency Coordinating Councils that advise and assist the lead agency responsible in each state for the implementation of Part H of the law.

# NEXT STEPS

As planners, administrators, parents, practitioners and advocates consider ways to use P.L. 99-457 and other resources to integrate mental health concepts and services into the care offered to young children and their families in their state, they may find the following questions useful guides to planning.

- 1. Is the state mental health agency included in the Interagency Coordinating Council under Part H of P.L. 99-457? Do subcommittees of the Council include individuals with expertise in infant mental health?
- 2. Does the lead agency with responsibility for administering Part H have access to mental health expertise, either within its staff or through collaborative arrangements?
- 3. Who currently provides mental health services for infants, toddlers and their families in the state? Is there a comprehensive directory of services that might be provided by community mental health centers, private non-profit clinics, private practitioners, therapeutic day care centers, family service and family resource agencies, early intervention programs, university affiliated programs, hospitals and other sources?
- 4. Are social-emotional and mental disorders, both primary or secondary to other disabilities and handicaps, included in operational definitions of handicapping conditions?
- 5. What funding sources exist for mental health services to infants, toddlers and families in the state? What are state Medicaid eligibility requirements, and what mental health-related services are reimbursed? What services are covered by private insurers in the state? What services are available through state maternal and child health programs, programs for



children with special health needs, community mental health centers, and state mental health agencies? Are these services free of charge to families? If not, how are fees determined?

- 6. What training in infant/toddler mental health is available in the state or region at preservice, in-service and continuing education levels? Is mental health training available to all disciplines concerned with young children and families? Is joint, interdisciplinary training available? What retraining opportunities exist for individuals with health or human services experience to acquire the specific skills needed to provide mental health services to very young children and their families?
- 7. What is the status of current or proposed legislation in the state that affects the mental and emotional well-being of infants, toddlers and their families? Does the state have a parental leave law? How is child care for infants and toddlers regulated? How do state laws address the continuum of care model: are there state funded family resource programs? Do child welfare laws support preventive approaches as well as out-of-home placement? What programs exist for adolescent and other high risk parents?
- 8. Are there statewide or cabinet-level policymaking bodies concerned with the well-being of children and families? Do these include a mental health focus?

## RESOURCES

The Child and Adolescent Service System Program (CA.SSP) of the National Institute of Mental Health will also be preparing papers that describe specific models and examples of the integration of mental health sensitivities, skills and services into community and state systems of care for infants and toddlers with disabilities or at risk of disability and their families. For further information on mental and emotional development in early childhood, on promising service approaches, on publications in the field, and on training opportunities, readers may wish to write or call the following organizations.

American Academy of Child and Adolescent Psychiatry (AACAP) 3615 Wisconsin Avenue, NW, Washington, DC 20016 (202) 966-7300

Contact: Virginia Q. Anthony Executive Director

AACAP was established in 1953; provides national continuing medical educational progress of child mental health care; publishes the Distinguished Journal of AACAP and quarterly newsletter; provides public information; works closely with child advocacy groups, parents, teachers and other mental health professionals; has led fight against child mental illness and been at forefront for optimal care for mentally ill children and their families.

## Association for the Care of Children's Health (ACCH) 3615 Wisconsin Avenue, NW, Washington, DC 20016 (202) 244-1801

### Contact: Mary McGonigel

Family Centered Care Project Coordinator ACCH is an international interdisciplinary association of parents and health care professionals which seeks to foster and promote the psychosocial wellbeing of children and families in health care settings. It distributes a variety of educational resources to assist health care professionals, educators and parents in humanizing health care for children.

#### CASSP Technical Assistance Center

Georgetown University Child Development Center 3800 Reservoir Road, NW, Washington, DC 20007 (202) 687-8873

Contact: Roxane Kaufmann

Director, Special Projects

The Child and Adolescent Service System Program's (CASSP)s Technical Assistance Center, part of the Georgetown University Child Development Center, is funded by the National Institute of Mental Health to provide training and support to states and communities in the development of service systems for emotionally disturbed children and adolescents. The center also develops and disseminates documents on a variety of topics relating to mental health systems, its components and their relationships to other human service systems. The Child Development Center also provides training and technical assistance through the National Center for Networking Community Based services, funded by Maternal and Child Health and is part of the National Early Childhood Technical Assistance System (NEC\*TAS) funded by the Office of Special Education Programs.

National Center for Clinical Infant Programs (NCCIP) 733 15th Street, NW, Suite 912 Washington, DC 20005 (202) 347-0308 Contact: Emily Schma or Elegnor Scanton

Contact: Emily Schrag or Eleanor Szanton

The National Center for Clinical Infant Programs, is a national multidisciplinary non-profit organization founded in 1977 to promote health, mental health and development in the first three years of life. NCCIP publishes a bulletin, *Zero to Three*, the Clinical Infant Report book series and other publications. It holds biennial national multidisciplinary training institutes in Washington, DC, as well as regional conferences. Special projects concern child care for infants and toddlers, diagnostic classification, and competencies for



practitioners working with infants, toddlers and families. NCCIP also coordinates Project Zero to Three, funded by Maternal and Child Health and is one of the participating agencies in the National Early Childhood Technical Assistance System (NEC\*TAS).

National Early Childhood Technico! Assistance System (NEC\*TAS)

CB#8040 500 NCNB Plaza Chapel Hill, NC 27599 (919) 962-2001 Contact: Pascal Trohannis Director

The National Early Childhood Technical Assistance System (NEC\*TAS) is funded through the Office of Special Education Programs to assist states, institutions and programs in providing multidisciplinary, coordinated, comprehensive services for children with special needs, birth to age 8, and their families. NEC\*TAS is comprised of five collaborating agencies representing professionals and parents.

National Network of Parent Centers (NNPC) 312 Stuart Street, 2nd Floor Boston, Massachusetts 02116 (617) 482-2915 Contact: Martha Ziegler Coordinator

NNPC consists of 65 coalitions of parents throughout the country that provide information and training for parents of children and infants with all disabilities. Network is one of the major collaborators in National Early Childhood Technical Assistance System. (NEC\*TAS).

International Association for Infant Mental Health (IAIMH) Michigan State University Department of Psychology Psychology Research Building East Lansing, MI 48824-1117 (517) 355-4599 Contact: Himm Fitzgenald, Ph.D. Executive Director

IAIMH, a clinical and advocacy-oriented association was established in 1979 for the purpose of promoting optimal development of infants and their families. There are currently 13 affiliate organizations nationwide.

Mental Hewith Law Project (MHLP) 2021 L Street, NW, Suite 800 Washington, DC 20036-4909 (202) 467-5730

Contact: Margaret Lorber/Beth Carter

Early Intervention Advocacy Program MHLP has set up an early intervention advocacy network for parents, disability groups, child advocacy groups, and private providers. The Early Intervention Advocacy Center will be providing technical assistance on organizing grass root support, issue papers and alerts, consultation on legal issues, and advocacy activities in other states.

National Alliance for the Mentally Ill (NAMI) 1901 North Fort Myer Drive, Suite 500 Arlington, VA 22209 (703) 524-7600

NAMI is a grass roots family-based self help organization concerned with serious mental illness. Membership includes parents, siblings, spouses and friends of people with mental illness, professionals and service providers, and the mentally ill themselves.

National Mental Health Association (NMHA) 1021 Prince Street Alexandria, VA 22314-2971 (703) 684-7722 Contact: Chris Koyanagi Director of Federal Relations

NMHA is a national, private, voluntary organization providing leadership to confront the entire range of mental health issues at local, state and national levels; provides technical assistance to local and state mental health association affiliates nationwide, and also acts as a resource and referral center on mental health issues.

World Association for Infant Psychiatry and Allied Disciplines (WAIPAD)
The Vision of Child Psychiatry
Louisiana State University Medical Center
1542 Tulane Avenue
New Orleans, Louisiana 70112-2822
(504) 568-6221
Contact: Joy D. Osofsky, Ph.D. Secretary General
WAIPAD, a clinical and research oriented associa-

WALFAD, a clinical and research oriented association, was established in 1980 for the purpose of promoting education and research in the fields of infant mental health. It recognizes that specialized study of infancy should take place within the context of the entire life cycle, including the succession of generations.

## APPENDICES

- A. Summary of P.L. 99-457
- B. List of 12/18 meeting participants
- C. List of state Part H lead agency contacts
- D. CASSP



# APPENDIX A PL 99-457 The New Law

by Barbara J. Smith, Ph.D.

## Background

For over 20 years, the federal government has been supporting research into the effectiveness of early intervention with handicapped and at risk young children and their families. In addition to research studies, projects have been funded to develop model practices for effective early intervention.

These research and model development projects, along with programs such as Head Start, have proven that early intervention is effective. We now know that if we provide support and services to children and families as early as the need is apparent, then: 1) the child's development will not be as delayed as it would be if left unattended until age 6 or older; 2) the stress for the family of having a handicapped child is lessened and they are able to function more productively; and, 3) because of these results, children and families are more able to contribute to their community indeed, early intervention can prevent the need for many costly services later in life.

In recognition of the effectiveness and critical importance of early intervention, the United States Congress passed Public Law 99-457 in September, 1986.

## Overview

F.L. 99-457, the Education of the Handicapped Act Arnendments of 1986, includes provisions for handicapped children of all ages, as well as for personnel and other activities. However, the most dramatic provisions of this new law relate to handicapped and 'at risk' children between the ages of birth and six and their families. Indeed, the law states:

"The Congress finds that there is an urgent and substantial need:

1) to enhance the development of handicapped infants and toddlers and to minimize their potential for developmental delay;

 to reduce the educational costs to our society, including our nation's schools, by minimizing the need for special education and related services after [they] reach school age;

3) to minimize the likelihood of institutionalization of handicapped individuals and maximize the potential for their independent living in society; and, 4) to enhance the capacity of families to meet the special needs of their infants and toddlers with handicaps."

Regarding young children and their families, P.L. 99-457 established two new federal programs. One new program addresses 3 through 5 year-old handicapped children, and the other addresses handicapped and at risk infants and toddlers from birth to age three.

# The Preschool Grant Program (3–5 year-olds)

First, P.L. 99-457 creates a new mandate for state education agencies to serve all three, four, and five year-old handicapped children by 1990-1991. This new preschool mandate was achieved by lowering the P.L. 94-142 mandate to age three. P.L. 94-142, the Education for All Handicapped Children Act of 1975, created a "right to education" for handicapped children between ages six and eighteen. However, to encourage states to serve children below the ages of six, Congress created the Preschool Incentive Grant in 1975, which, instead of mandating, simply provided some incentive monies. Now this "right to education" is extended to children beginning at age three.

This new Preschool Grant Program changes the old Preschool Incentive Grant in several ways—it is, in fact, a mandate, rather than an incentive, and it provides more than three times the funding for 3-5 year-olds!

Dr. Barbam J. Smith completed her doctorate in Special Education at the University of North Carolina. She has served as a member of the CEC Governmental Relations Staff and most recently as a special consultant to CEC in working with the congressional committees of Senator Lowell Weicker and Congressman Pat Williams, which formulated P.L. 99-457.

Dr. Smith is recognized as a national leader in policy issues regarding the education of young handicapped children. Her paper, which is presented here, was written at the invitation of the Chapel Hill Training Outreach Project.



## Who are the Eligible Children?

The Preschool Grant Program's purpose is to extend P.L. 94-142 rights to children from age three, including all definitions and requirements. Moreover, three, tour and five year-olds are eligible for services under this new program if they are handicapped according to one or more of the P.L. 94-142 diagnostic categories: deaf, deaf-blind, hard of hearing, mentally retarded, multihandicapped, orthopedically impaired, other health impaired, seriously emotionally disturbed, specific learning disability, speech impaired, and visually handicapped.

However, Congress made an important distinction for the preschooler: the documentation and count of children required by the federal government from the states does not have to be by diagnostic category for this age group. This allows states to serve 3-5 yearolds without labeling them.

P.L. 94-142 was changed a second way for this age group: parental instruction is an allowable cost, rather than only services delivered directly to the child. This was in recognition of the important role parents play in the lives of pre-school-aged children. Finally, P.L. 99-457 pre-school services differ from school-aged requirements under P.L. 94-142 in that variations in length of day, or service model (home-based, centerbased, etc.) are encouraged. Also, local education agencies are encouraged to contract with appropriate existing non-public school community preschool programs to provide a range of services and service models such as the mainstreaming opportunities offered by Head Start.

## What is Mandated and When?

P.L. 99-457 requires that states, through their state education agencies, participating under P.L. 94-142, ensure that they are providing a "free, appropriate, public education" to all handicapped children beginning at age three, by 1990-91. Currently, all states ensure that they are providing appropriate services, including individualized education programs (IEP), due process, least restricted environment, non-discriminatory testing, parent involvement, and support services to all handicapped children beginning at age six. About half the states currently serve three, four, and five year-olds.

# What is the Funding Level?

The Preschool Grant Program has two channels of funds: a) one for reimbursing school districts for children served in the previous year (served children); and, b) one for advance payment for the number of additional children the state reports they *intend* to serve the following year (unserved children).

Served children will generate up to \$300/child in fiscal year 1987; \$400/child in fiscal year 1988; \$500/child in fiscal year 1989; and \$1,000/child thereafter. Unserved children generate up to \$3,800/child until 1990, then all children generate up to \$1,000/child.

If the state does not, in fact, serve all the unserved children they intended to serve and received advanced payment for, their next year's allocation will be adjusted downward. Similarly, if the state serves more unserved than intended, the following year's allocation is adjusted upward.

# What Happens if a State does not Comply?

If a state does not ensure a free, appropriate, public education beginning at age three to all handicapped children by 1990-91, it will lose the following federal funds:

- all Preschool Grant Funds;

- all P.L. 94-142 dollars that were generated by the 3-5 year-olds;

— and all grants and contracts related to preschool special education funded under the Education of the Handicapped Act discretionary programs.

## Handicapped Infants and Toddlers Program

The second landmark early intervention program established by P.L. 99-457 is the Handicapped Infants and Toddlers Program. This section of the law creates a brand new federal program for handicapped and at risk children from birth to age three years and their families. The Congressional purpose of this program is to provide financial assistance to states to:

1) develop and implement a statewide, comprehensive, coordinated, multi-disciplinary, 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 states' capacities to provide quality early intervention services.

While the infant and toddler program is voluntary for states—that is, they may elect to not participate—if a state does choose to participate, or apply for funding under this law, it must meet the requirements of the law. And, to be eligible for a grant in the fifth year, the state must assure that services are available to all eligible children.



15

. i ,

## Who is Eligible for Services?

The new Infant and Toddler Program is directed to the needs of children, birth to their third birthday, who need early intervention because they

1) are experiencing developmental delays in one or more of the following areas: cognitive, physical, language and speech, psychosocial, or self-help skills; or

2) have a physical or mental condition that has a high probability of resulting in delay (e.g., Down's Syndrome, cerebral palsy, etc.); or

3) at state discretion, are at risk medically or environmentally for substantial developmental delays if early intervention is not provided.

Secondly, the infant and toddler's family may receive services under this program that are needed to facilitate their capacity to assist in the development of their child.

## What Must States Provide?

If a state applies for funds under this program, it must meet the following requirements:

#### The first two years:

1) the governor has established an Interagency Coordinating Council made up of parents, providers, state agency representatives, personnel trainers, state legislative representatives, and others;

2) the governor has designated a lead agency (which may be the Interagency Coordinating Council); and,

3) the state assures that the funds will be used to plan, develop and implement statewide services.

### The third and fourth years:

1) in addition to the requirements of the first two year the state must assure that it has adopted a policy which contains the required components of a statewide system, which are:

• A definition of the term "developmentally delayed"

• Timetables for ensuring services to all eligible children by the fifth year of participation

• Multidisciplinary evaluations of the functioning of all eligible children and the needs of their families to assist in the development of their child

• Provision of a written individualized family service plan (IFSP) for all children

• Comprehensive Child Find system including a system for making referrals to providers. "Primary referral sources" must be included—including hospitals, physicians, other health care providers and agencies, and daycare facilities

• A public awareness program focusing on early identification

 A central directory containing State resources, services, experts, and research and demonstration projects

• A comprehensive system of personnel development—including training of public and private service providers, primary referral sources, as well as pre-service training.

 The system must include a single line of authority in a *lead agency* designated or established by the Governor to carry out: the general administration, supervision, and monitoring of programs and activities; the identification and coordination of all available resources within the state from federal, state, local and private sources and the assignment of financial responsibility to the appropriate state agency; the resolution of state interagency disputes and procedures for ensuring the provision of services pending the resolution of such disputes; and, the entering into formal state interagency agreements that define the financial responsibility of each state agency for paying for early intervention services (consistent with state law) and include, among other things, procedures for resolving dispute

• A policy pertaining to the contracting or making of other arrangements with local providers

• A procedure for securing timely reimbursements of funds between state and local agencies

• Procedural safeguards with respect to the settlement of disagreements between parents and providers, the right to appeal, the right to confidentiality of informatior, the opportunity to examine records, assignment of surrogate parents, written prior notices to parents in their native language, and procedures to ensure the provision of services pending the resolution of complaints

• Policies and procedures relating to the establishment and maintenance of personnel training, hiring, and certification/licensing standards

• A system for compiling data on the early intervention programs (may include sampling).

2) And that the statewide system will be in effect no later than the beginning of the fourth year, except for the assurance of full service to all eligible children.

### The fifth and succeeding years:

1) The state must assure that the system is in effect and full services are available to eligible children.

Early intervention services must include, for each eligible child, a multidisciplinary assessment and a written Family Service Plan (IFSP) developed by a multidisciplinary team and the parents. Services which may be provided must be designed to meet the developmental needs of the child and be in accordance with an IFSP and may include special education, speech and language pathology and audiology, occupational therapy, physical therapy, psychological services, parent and family training and counseling services, transition services, medical services for diagnostic purposes, and health services necessary to



enable the child to benefit from other early intervention services. Case management services must be provided for every eligible child and his/her parent.

All early intervention services must be provided at no cost to parents except where federal or state law provides for a system of payments by parents, including provision for a schedule of sliding fees.\*

## What are the Individualized Family Service Plan (IFSP) Requirements?

The IFSP must be developed by a multidisciplinary team and contain: (a) a statement of the child's present levels of development (cognitive, speech/language, psychosocial, motor, and self-help); (b) a statement of the family's strengths and needs relating to enhancing the child's development; (c) a statement of major outcomes expected to be achieved for the child and family; (d) the criteria, procedures, and timelines for determining progress; (e) the specific early intervention services necessary to meet the unique needs of the child and family including the method, frequency, and intensity of service; (f) the projected dates for the initiation of services and expected duration: (g) the name of the case manager; and, (h) procedures for transition from early intervention into the preschool program.

The IFSP must be evaluated at least once a year, and must be reviewed every six months or more often where appropriate.\*

## What is the Funding Level?

Congress authorized \$50 million for Fiscal Year 1987, \$75 million for Fiscal Year 1988, and such sums as may be necessary thereafter.

Funds are to be distributed to the states based upon the relative number of infants, birth to three, in the state compared to other states; that is, based on census, not actual, child count.

## Implications

As in all new nationwide or statewide efforts, there are many implementation issues to solve and to discuss. P.L. 99-457 stresses the importance of a coordinated and multi-agency approach to the planning and dialogue that is necessary to implement the new early childhood initiatives. Indeed, a critical component of the new programs is the acknowledgment that a wide variety of local providers (public and private) should be contracted with in order to meet the requirements of the Act in a cost-effective way, while also providing a continuum of services to meet the individual needs of children and families. Secondly, the Infants and Toddlers Program mandates each state to establish an Interagency Coordinating Council to facilitate such a multiagency dialogue. Interested individuals, providers, and parents have many opportunities to influence state and local implementation of P.L. 99-457. Local interagency groups should begin to discuss and plan the state and local solutions to early intervention and preschool services in their area.

At least two policy issues will dramatically influence implementation in each state, and both require input from all concerned groups. These two issues are the development of program standards and personnel standards. Each state will need to establish standards which agencies may use to evaluate appropriate placement options for children. In order to meet the wide variety of needs of children and families, these standards should be as inclusive as possible while also ensuring a high quality of service. Program standards should be developed to address the full continuum of services-from center-based specialized settings to child care and other community mainstreamed settings. Personnel standards will need to address professional and paraprofessional competencies across many disciplines. Standards should acknowledge the unique needs of the birth to five population, while also acknowledging the important role current providers play.

Creative solutions will be necessary in order to address the unique needs of the population while a shortage of available personnel exists. Training new personnel and providing in-service training to current personnel who either need certification/licensing, or who need added competencies to meet the needs of very young children, will be critical. Secondly, solutions that provide the availability of integrated or mainstreamed settings will reflect what we know to be important for young handicapped children—that they have the opportunity to learn and interact with normally developing peers.

There are many models nationwide that currently address these and other issues. By working together, parents and providers can find the solutions that meet their local needs.

\*These descriptions are taken from materials provided by the Council for Exceptional Children.



# APPENDIX B participants list

#### MENTAL HEALTH/P<sup>7</sup>, 99-457 MEETING Old Town Holiday Inn Alexandria, Virginia Friday, December 18, 1987

Kris Hansen Mental Health/Head Start Project Georgetown University Child Development Center 3800 Reservoir Road, NW Washington, DC 20007 (202) 687-8873

Edward Hinkley Bureau of Children with Special Needs Department of MH/MR State House Station #40 August, ME 04333 (207) 289-4250

Naomi Karp Program Specialist National Institute on Disability and Rehabilitation Fasearch Mail Stop 2305, Switzer Building 330 C Street, SW, Room 3424 Washington, DC 20202 (202) 732-1196

Judith Katz-Leavy Deputy Director, CASSP NIMH 5600 Fishers Lane, 7-C-14 Rockville, MD 20857 (301) 443-1333

Roxane Kaufmann Child Development Center Georgetown University 3800 Reservoir Road, NW, CG-52 Washington, DC 20057 (202) 687-8873

Victoria Levin Prevention Research Branch NIMH 5600 Fishers Lane, 14-C-03 Rockville, MD 20857 (301) 443-4283

Ira Lourie Director, CASSP NIMH 5600 Fishers Lane, 7-C-14 Rockville, MD 20857 (301) 443-1333 Phyllis Magrab Director Child Development Center Georgetown University 3800 Reservoir Road, NW, CG-52 Washington, DC 20057 (202) 687-8635

Merle McPherson Acting Director Division of Services for Children With Special Health Needs Bureau of MCH Room 6-40, Parklawn 5600 Fishers Lane Rockville, MD 20857 (301) 443-2350

Gloria Morote Psychologist South C.M.H.C. 1927 Marthas Road Alexandria, VA 22307 (703) 727-9043

Jeree Pawl Director c Infant Parent Program San Francisco General Hospital Bldg. 90, Ward 95 2460 22nd Street San Francisco, CA 94110 (415) 821-5289

Eugene Perrotta Division of Health Services P.O. Box 2091 Raleigh, NC 27602 (919) 733-7437

Emily Schrag National Center for Clinical Infant Programs 733 15th Street, NW, #912 Washington, DC 20005 (202) 347-0308

Patricia McGill Smith Deputy Assistant Secretary OSERS 330 C Street, SW Room 3006 Switzer Washington, DC 20202 (202) 732-1265

May Aaronson CASSP NIMH 5600 Fishers Lane, 7-C-14 Rockville, MD 20854 (301) 443-1333

Marva Benjamin Executive Director Elahan Center for Mental Health and Family Living 3265 N.E. U.S. Grant Place Portland, Oregon 97212 (206) 695-3416

Paula Clark Division of MH/MR/SAS Dept. of Human Resources 325 N. Salisbury Street Raleigh, NC 27611 (919) 733-4660

Conchita Espino Dept. of Human Services P Street Clinic 3246 P Street, NW Washington, DC 20007 (202) 282-0027

Ed Feinberg Director Parent Infant Program 160 Funke Road Glen Burnie, MD 21061 (301) 761-7196

Linda Gilkerson Behavioral and Dev. Pediatrics Evanston Hospital 2650 Ridge Avenue Evanston, IL 60201 (312) 492-2758

Stanley Greenspan Infant Psychiatrist 7201 Glenbrook Road Bethesda, MD 20814 (301) 654-2348 Eleanor Stokes Szanton Director National Center for Clinical Infant Programs 733 15th Street, NW, #912 Washington, DC 20005 (202) 347-0308 Richard Westgard CASSP Project Director Dept. of Social and Health Services Mental Health Division Mailstop OB-42F Olympia, WA 98504 (206) 586-3775 Lu Ann White Parent 78 North Main Street Orono, ME 04473 (207) 941-2840

# APPENDIX C

# Infant/Toddler (Part H) Lead Agencies

Charles Ryalls, Director Crippled Children Service Department of Education 2129 E. South Boulevard Montgomery, AL 36111 (205) 281-8780

Rita Schmidt, Chief Section of Family Health Dept. of Health & Social Services 1231 Gambell Street Anchorage, AK 99501-3037 (907) 274-7626

Charles R. McCuddin, Director Department of Health LBJ Tropical Medical Center Government of American Samoa Pago Pago, AS 96799 011 (684) 633-2732

Eddie F. Brown, Director Department of Economic Security 1717 West Jefferson Street P.O. Box 6123 Phoenix, AZ 85005 (602) 255-5678

Ann Majure, Deputy Director Division of Developmental Disabilities Services Department of Human Services P.O. Box 1437 Waldon Building, 5th Floor Little Rock, AR 72203-1437 (501) 682-8662

Charles Cordova, Chief Branch of Exceptional Education Office of Indian Education Pgms. Bureau of Indian Affairs MS 4659 (MIB) 18th and C Streets, NW Washington, DC 20245 (202) 343-1990 or -4071 Gary D. Macomber, Director Dept. of Developmental Services 1600 9th Street Sacramento, CA 95814 (916) 323-3131

Brian McNulty, Exec. Director Special Education Services State Department of Education 201 East Colfax Street Denver, CC 80203 (303) 866-6:94

Gerald N. Tirozzi Commissioner of Education State Dept. of Education Box 2219 Hartford, CT 06145 (203) 566-5061

Carl M. Haltom, Director Exceptional Children and Special Programs Department of Public Instruction P.O. Box 1402 Dover, DE 19903 (302) 736-5471

M. Jerome Woods, Acting Dir. Department of Human Services 801 North Capitol Street, N.E. Suite 700 Washington, DC 20002 (202) 727-0310

Betty Castor, Commissioner State Department of Education Capitol Building, Room PL 116 Tallahassee, FL 32399 (904) 487-1785

James G. Ledbetter, Commissioner Department of Human Resources 47 Trinity Avenue, S.W. Atlanta, GA 30334-1202 (404) 656-5680 Rosa S. Palomo Director of Education Department of Education P.O. Box DE Agana, GU 96910 011 (671) 472-8901

John C. Lewin, M.D., Director Department of Health P.O. Box 3378 Honolulu, HI 96801 (808) 548-6505

Richard P. Donovan, Director Dept. of Health and Welfare 450 West State Street Boise, ID 83720 (208) 334-5500

Ted Sanders Superintendent of Education State Board of Education 100 North First Street Springfield, IL 62777 (217) 722-4321

Dennis R. Jones, Commissioner Department of Mental Health 117 East Washington Street Indianapolis, IN 46204 (317) 232-7844

William Lepley Director of Education State Dept. of Education Grimes State Office Building Des Moines, IA 50319-0146 (515) 281-5294

Patricia T. Schloesser, M.D., Health Director State Department of Health & Environment Landon State Office Building 900 S.W. Jackson, Room 905 Topeka, KS 66620-0001 (913) 296-1343



Jim Henson Division of Mental Health Services Department of Mental Health & Mental Retardation 275 East Main Street Frankfort, KY 40621 (502) 564-7700

Elizabeth Borel, Asst. Supt. Office of Special Educational Svcs. State Department of Education P.O. Box 94064 Baton Rouge, LA 70804-9064 (504) 342-3631

Rollin Ives, Chair Interdepartmental Council Department of Human Services State House, Station #11 Augusta, ME 04333 (207) 289-2736

Administrative Officer Governor's Office for Children and Youth 1123 N. Eutaw St., Room 601 Baltimore, MD 21201 (301) 333-5800

Deborah Protherow-Stith, Commissioner State Department of Public Health 150 Tremont Street Boston, MA 02111 (617) 727-2700

Gary D. Hawks, Superintendent of Public Instruction State Department of Education P.O. Box 30008 608 West Allegan Street Lansing, MI 48909 (517) 373-3354

Jim Sauter, Deputy Commissioner State Department of Education 712 Capitol Square Build. 5 550 Cedar Street St. Paul, MN 55101 (612) 296-2358

Alton B. Cobb State Health Officer State Board of Health P.O. Box 1700 2423 North State Street Jackson, MS 39215-1700 (601) 960-7634 Robert E. Bartman, Commissioner Department of Elementary and Secondary Education P.O. Box 480 Jefferson City, MO 65102 (314) 751-4446

Dennis Taylor, Administrator Developmental Disabilities Div. Department of Social and Rehabilitation Services P.O. Box 4210 Helena, MT 59604 (406) 444-2995

Joseph E. Lutjeharms Commissioner of Education State Department of Education P.O. Box 94987 Lincoln, NE 68509 (402) 471-2465

Jerome Griepentrog, Director Department of Human Resources 505 East King Street Carson City, NV 89710 (702) 885-4400

John T. MacDonald, Commissioner State Department of Education State Office Park South 101 Pleasant Street Concord, NH 03301 (603) 271-3144

Jeffrey V. Osowski, Director Division of Special Education State Department of Education 225 West State Street, CN 500 Trenton, NJ 08625 (609) 292-0147

Larry Gordon, Secretary Dept. of Health and Environment P.O. Box 968 Santa Fe, NM 87504-0968 (505) 827-2623

Monica Meyers, M.D. Department of Health Corning Tower, Room 780 Empire State Plaza Albany, NY 12237 (518) 474-2084

David T. Flaherty, Secretary Department of Human Resources 325 North Salisbury Street Raleigh, NC 27611 (919) 733-4534 John A. Graham, Exec. Director Department of Human Services State Capitol Birmarck, ND 58505 (701) 224-2310

Henry I. Sablan Commissioner of Education Public School System Commonwealth of the Northern Mariana Islands Lower Base Saipan, CM 96950 011 (670) 322-9817

Ronald Fletcher, M.D., Director State Department of Health P.O. Box 118 Columbus, OH 43266-0118 (614) 466-2253

Connie Siler, Director Special Education Services State Department of Educaton 2500 North Lincoln Blvd., Suite 263 Oklahoma City, OK 73105 (405) 521-3351

Michael Lincicum, Acting Dir. Department of Human Resources Mental Health Division 2575 Bittern Street, N.E. Salem, OR 97310 (503) 378-2671

William Tabelual, Director Bureau of Education Department of Social Sciences P.O. Box 189 Koror, Palau 96940 Phone: 01-952

John F. White, Secretary Department of Public Welfare Health & Welfare Bldg., Rm. 333 Harrisburg, PA 17120 (717) 787-2600

Awilda Aponte Roque Secretary of Education Department of Education P.O. Box 759 Hato Rey, PR 00919 (809) 751-5372

Thomas Kochanek, Exec. Director Interagency Cocrdinating Council Department of Special Education Rhode Island College 600 Mt. Pleasant Avenue Providence, RI 02908 (401) 456-8599



Michael D. Jarrett, Commissioner Department of Health and Environmental Control 2600 Bull Street Columbia, SC 29201 (803) 734-4880

Henry G. Kosters, State Superintendent Division of Education Department of Education and Cultural Affairs 700 Governors Drive Pierre, SD 57501-3133 (605) 773-3243

Charles E. Smith Commissioner of Education State Department of Education 100 Cordell Hull Building Nashville, TN 37219 (615) 741-2731

Mary Elder, Administrator Early Childhood Intervention Pgm. State Department of Health 1100 West 49th Street Austin, TX 78756 (512) 465-2671 Peter C. Van Dyck, Director Family Health Services Division State Department of Health P.O. Box 16650-20FHS Salt Lake City, UT 84116-0650 (801) 538-6161

Stephen S. Kaagan Commissioner of Education State Department of Education 120 State Street Montpelier, VT 05602-2703 (803) 828-3135

Deborah McGregor, M.D., Acting Commissioner Department of Health Knud Hansen Complex St. Thomas, VI 00802 (809) 774-6097

Howard M. Cullum, Commissioner Department of Mental Health, Mental Retardation and Substance Abuse Services P.O. Box 1797 Richmond, VA 23214 (804) 786-3921 Norm Zimlich, Director Department of Social and Health Services Olympia, WA 98504-0095 (206) 753-6050

David K. Heydinger, Director State Department of Health 1800 Washington Street, East Charleston, WV 25305 (304) 348-2971

Timothy F. Cuhen, Secretary Department of Health & Social Services P.O. Box 7850 Madison, WI 53707 (608) 266-3681

Steven E. Zimmerman, Administrator
Division of Community Programs
Department of Health and Social Services
359 Hathaway Building
Cheyenne, WY 82002
(307) 7777094

# APPENDIX D

# CHILD AND ADOLESCENT SERVICE SYSTEM PROGRAM Annual Report

The Child and Adolescent Service System Program (CASSP) is an initiative to improve service delivery for severely emotionally disturbed children and adolescents by changing the way in which services to this population are delivered by States and communities. Based on the philosophy that these children and youth require a multi-agency approach, CASSP encourages the inter-agency coordination and planning of services, as well as, the development of a stronger mental health component within the broader child serving system. In order to best respond to the needs of the population, CASSP encourages families of severely emotionally disturbed children and adolescents to be included in the planning and implementation of such service systems and to act as a voice to support the development of an adequate and appropriate range of service options. The development of services appropriate for the needs of minority children and youth is also stressed.

## History

In 1984 Congress earmarked \$1.5 million to develop a new initiative to improve service delivery for severely emotionally disturbed children and adolescents. From this congressional mandate to develop new service delivery systems, the National Institute of Mental Health developed the Child and Adolescent Service System Program (CASSP), within what is now known as the Division of Education and Service Systems Liaison.

CASSP began as a \$1.5 million program which supported 10 State grants as well as small technical assistance and evaluation programs. With a Fiscal Year 1988 appropriation of \$7.4 million, CASSP has grown into a program that, through its grant and technical assistance activities, impacts the seriously emotionally disturbed (SED) children and adolescents in over three quarters of the States in the country; and



through its technical assistance impacts the entire country and the 3 million SED youngsters under the age of eighteen living in the United States today.

The grant program consists of 28 State and 11 community level grants (with the anticipation of 10 more State grants this fiscal year). The technical assistance program has expanded to include two Research and Training Centers, funded through an inter-agency agreement with the National Institute of Disability and Rehabilitation Research (NIDRR) in the Department of Education, and a major Technical Assistance Center, funded through an intra-agency agreement with the Division of Maternal and Child Health (MCH), of the Health Resources and Service Administration. An internal evaluation program measures the progress toward the program goals. This year CASSP has also expanded its programs to explore the system development needs of children and adolescents at high risk for severe emotional disturbance, namely children and adolescents who are homeless, those with AIDS, and infants and toddlers with disabilities included under P.L. 99-457, the 1986 Amendments to the Education of the Handicapped Act.

The population focus for CASSP are those severely mentally or emotionally disturbed individuals who are under the age of 18 (with certain exceptions), whose disabilities are so severe as to require long-term intervention by mental health and other related agencies. This definition is broad, with the understanding that States and communities will refine the definition to meet their specific needs.

The major goals of CASSP are to:

- Improve the availability of continuums of care for severely emotionally disturbed children and adolescents, and thus improve the availability and access to appropriate services across child service systems
- Develop leadership capacity and increase priority in allocations of resources for child and adolescent mental health services
- Establish coordination mechanisms and thereby increase levels of collaboration and efficiency of service delivery among agencies
- Develop structures for family participation in the planning and development of service systems, treatment options and individual service planning
- Ensure that all services provided by States and communities to SED children from culturally and/or ethnically diverse backgrounds are sensitive to those differences and are designed to appropriately fit within the cultural norms of the child or family receiving services.
- Develop the capacity for, and provide technical assistance on child and adolescent service system development
- Evaluate the principles and practices of CASSP.

## Technical Assistance and Research Program

The CASSP technical assistance and research program consists of three major components. These include: (1) the development and expansion of a critical knowledge base related to service system delivery as it impacts severely emotionally disturbed children and their families; (2) knowledge dissemination and exchange through resources and materials, training, direct provision of technical assistance and presentations at parent and professional meetings; and (3) work with other agencies at the Federal and State level, and other national organizations (including professional, parent, and citizen groups) concerned with improving services for severely emotionally disturbed children and adolescents.

During the past 3 years, CASSP has realized significant achievement in all three areas. The centerpiece of the CASSP TA program is A System of Care for SED Children by Beth Stroul and Robert Friedman. This monograph has been called a "blueprint for action in the child mental health field" and it continues to provide the overarching philosophy and conceptual framework for CASSP. The CASSP funded Technical Assistance Center at Georgetown University has focused on the provision of direct technical assistance to CASSP grantees and other interested States. They also perform state of the art studies on topics such as residential and day treatment, community based service alternatives for seriously emotionally disturbed children and the financing of mental health services for SED children and adolescents. Each study has resulted in a major publication.

In addition to the CASSP Technical Assistance Center, NIMH has co-funded with the National Institute for Handicapped Research two Research and Training Centers focusing on Seriously Emotionally Disturbed Children and Adolescents. These are located at the Florida Mental Health Institute of the University of South Florida in Tampa, Florida, and, at the Regional Research Institute of Portland State University in Portland, Oregon. Tasks have been divided so that the Florida Center is focusing primarily on the epidemiological and State systems analysis areas; with the Portland Center focusing on family support, model development and dissemination.

### **Evaluation Program**

The evaluation program, which was initiated in the first few months of CASSP, has made significant progress. An evaluation committee, made up of State representatives, NIMH staff and representatives of the Georgetown Technical Assistance Center's Advisory Board, provides the leadership for the design and implementation of the CASSP evaluation program. A goal of the evaluation program is designed around three components. These three components are: (1) a self-assessment instrument, (2) State/program specific evaluations, (3) a systems change evaluation.

