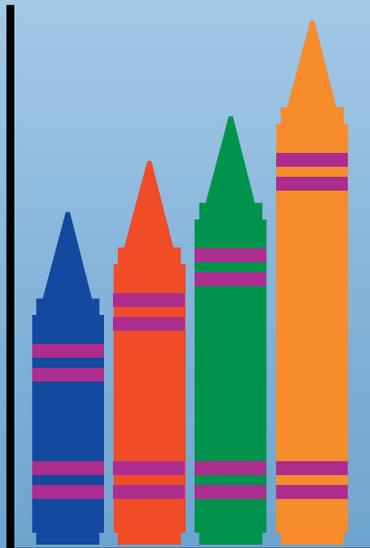


Pathways to Service Utilization: A Synthesis of Evidence Relevant to Young Children with Challenging Behavior



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Center for Evidence-Based Practice:
Young Children with Challenging Behavior

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May 30, 2003

Prepared by the

Center for Evidence-based Practice: Young Children with Challenging Behaviors
(H324Z010001)
funded by the Office of Special Education Programs, U.S. Department of Education

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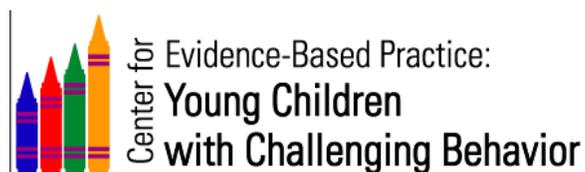
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Recommended Citation for this work: Powell, D., Fixsen, D., & Dunlap, G. (2003). Pathways to Service Utilization: A Synthesis of Evidence Relevant to Young Children with Challenging Behavior. Tampa, Florida: University of South Florida, Center for Evidence-Based Practice: Young Children with Challenging Behavior.

Preparation of this report was supported through a cooperative agreement from the U.S. Office of Special Education Programs, U.S. Department of Education (award # H324Z010001). Information or opinions contained in this document are those of the authors and do not represent agency endorsement or official agency positions.

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About the Center . . .

The Center for Evidence-Based Practice: Young Children with Challenging Behavior is funded by the U.S. Department of Education Office of Special Education Programs to raise the awareness and implementation of positive, evidence-based practices and to build an enhanced and more accessible data base to support those practices.

Pathways to Service Utilization: A Synthesis of Evidence Relevant to Young Children with Challenging Behavior

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Executive Summary

This document presents a synthesis of current knowledge pertaining to the utilization of services by young children with challenging behaviors and their families. In this document, challenging behavior is defined as any repeated pattern of behavior, or perception of behavior, that interferes with or is at risk of interfering with optimal learning or engagement in pro-social interactions with peers and adults. Challenging behavior is thus defined on the basis of its effects.

The purpose of the synthesis is to present a concise picture of the state of empirical knowledge relating to the identification, screening, referral, and entry into service systems for young children with challenging behaviors. This picture is intended to convey the nature of what is known about service utilization and, also, to identify the most conspicuous gaps in current knowledge. The delineation of gaps should then inform the field about prominent needs to be addressed by applied research. The review of the literature revealed that the data base on service utilization is sparse and there is essentially no experimental research available to compare and contrast different approaches to identification, screening, referral or access to service.

Studies of the rates at which behavior problems occur in young children have used a wide variety of methodologies, instruments and populations. Thus it is not surprising that the studies have resulted in a range of **prevalence** estimates. For samples of young children identified through healthcare visits, estimates of psychosocial problem rates are between 10% and 21%, while rates for externalizing problems are between 7% and 17%. Within kindergarten and preschool populations, rates of 8% to 25% for externalizing behavior problems have been found. For Head Start children, estimated prevalence rates vary from 10% to 23% for externalizing behaviors. These estimates have a somewhat higher upper range than that estimated by Campbell (1995) in her review of prevalence studies of behavior problems in young children which concluded that “roughly 10-15% of preschool children have mild to moderate problems” (p. 117).

No studies of prevalence rates for disorders in community samples of children under two years of age were found. This may well be due to the evolving nature of classification systems of infant disorders and the problems inherent to such systems, including the rapid development rates of infants, their inability to report their own experience and their more limited repertoire of behavior compared to older children.

In recognition of the extent of these challenging behaviors, federal **laws and policies** mandate screening, identification, and referral services for a significant portion of young children with challenging behavior.

The knowledge base regarding service utilization for young children with challenging behavior yielded several major conclusions. The overarching conclusion is that current systems are inadequate to serve the needs of young children with challenging behavior. In addition, there is little evidence that services are accessed across and between systems in a coordinated manner that expedites comprehensive care for young children.

The **health care system** is a primary gateway for identification, screening, referral, and access to services for young children with challenging behavior. Thus, access to health care and the practices of pediatricians are extremely important elements in determining whether a child receives services. Three federal programs facilitate access to health insurance for low-income young children: Medicaid, the State Children's Health Insurance Program, and the Maternal and Child Health Block Grant Program. Additionally, the American Academy of Pediatrics has developed a policy on Developmental Surveillance and Screening of Infants and Young Children. Virtually all preschool children could be contacted by screening and identification practices contained in the health care system. However, fewer than 1/3 of the eligible children receive a full EPSDT screen and even fewer receive a screen that includes behavioral health.

Medicaid mandates further testing or assessment for those young children screened positive for challenging behavior. However, few behavioral health services were actually being delivered to this population (e.g., 56% of states reported that their Medicaid reforms were providing few or no behavioral health services to the early childhood population). This may be due, in part, to the fact that pediatricians correctly identify only a small portion of young children with challenging behavior (estimates range from 17% to 40%).

Because large numbers of young children spend time in **out-of-home care** arrangements, these settings provide important opportunities for identifying children with challenging behavior and forming connections to services. Federally supported early care and education programs (not including IDEA programs) include Head Start, Early Head Start, Title I and the Child Care and Development Fund (CCDF). Only Head Start, Early Head Start and Title I mandate screening and mental health services. In addition, 39 states fund prekindergarten programs; 14 of these mandate developmental screening.

Children placed in **child welfare** services often have a complex array of challenging behavior and consume a disproportionate share of resources devoted to the problems of young children. Child welfare encompasses protective services, family reunification, foster care, and adoption. While each state has its own child welfare system funded and administered by the state, approximately 45 % of the funding for state systems comes from the federal government. There are six major federal programs that provide funding to states for child welfare (Social Security Act Child Welfare Services Program, Promoting Safe and Stable Families Program, Foster Care and Adoption Assistance Program, and Social Services Block Grants; Child Abuse Prevention and Treatment Act; and Adoption and Safe Families Act); all six are administered through the

Administration for Children and Families, DHHS. None of these programs contain mandates for mental health screening or services.

The Community **Mental Health** Services Block Grant Program (CMHSBG), administered through The Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, awards grants to states for services to adults and children with serious mental disorders. The grants are designed to support existing public services and the development of systems of community-based care. However, there is little regulation on how the funds are to be spent by states. Because of the competing demands on these funds and the requirement that they be used for children with severe emotional disturbance, very little of the money is spent on services for children under six years and there is no mandate or set-aside funds for prevention. As a result, Mental Health Systems for very young children are almost non-existent.

The **Individuals with Disabilities Education Act** (IDEA) Part B program provides funding for educational and related services to preschoolers (ages 3-5 years) with disabilities while the Part C program provides funding for early intervention services for children 0-2 years with disabilities. While the law does mandate critical components, states also have broad latitude in how they administer and implement the mandates and in determining outcomes and indicators. Each state must designate a lead agency and these vary from state to state. Currently, health is the lead agency in 14 states, education is the lead agency in 13 states, and a combined department of health and human or social services is the lead agency in 9 states. While IDEA Part C and Part B programs are a primary resource for identifying young children with suspected disabilities, including behavior challenges, the effectiveness of these systems in identifying young children with challenging behavior is unknown.

The **synthesis** of the knowledge base regarding service utilization for young children with challenging behavior yielded the following major conclusions:

- Young children with challenging behavior can be identified among those in the preschool environments, however biases may exist in identification and referral systems for young children with challenging behavior.
- With respect to service utilization, young children use mental health services at rates lower than the projected need.
- Studies indicate that service utilization for young children with challenging behavior is mostly governed by medical professionals.
- Family factors, education, race, and income impact the availability of services and utilization of services for young children with challenging behavior in early intervention systems.
- There is a high need for mental health services within Head Start but resources are not always available to meet the need.
- Family-centered practices and a broader approach to young children with challenging behavior is needed in child care systems.
- Children in child welfare systems, foster care in particular, utilize a disproportionate share of the mental health services available to young children with challenging behavior.

These conclusions are based on little data, so it is important to recognize them as tentative. As shown in this synthesis, there is insufficient evidence to draw very definite conclusions. The gaps in knowledge are glaring and will require a concerted research effort over many years to fill in the blanks so more reasoned and effective policies and procedures can be enacted and implemented on a national basis. This is, however, an important item on the national agenda. Many of the more severe forms of health, mental health, educational, social service, and child caring problems seen later in life have their roots firmly planted in the preschool developmental years. Future generations stand to benefit greatly from a more reasoned and integrated effort to detect and treat the earliest problems associated with young children with challenging behavior.

The following **recommendations** are based on the information (and lack of information) reviewed in this document:

(1) Screening and identification of young children with challenging behavior needs to be based on a growing body of literature that relates problems of early childhood development with later behavioral health problems. In this way, screening can more effectively and efficiently identify those problems most predictive of later, more severe challenging behaviors. In particular, there is a need for longitudinal research, retrospective and prospective, that carefully charts the development of challenging behaviors in the preschool years and research to evaluate screening systems that are practical for use at a community level and in primary health care settings.

(2) Research is needed to develop referral systems that are attuned to the needs of families and the variety of services available in order to match needs with appropriate services. This is a critical step in the process of ameliorating challenging behavior at an early stage. The “hand-off” from the screening-identification systems needs to be seamless and engaging for families so they will actually contact the help that is needed.

(3) Given the prevalence of challenging behavior among preschool children, research is needed to help establish supports and services that are available nationally to children and families. These evidence-based programs would help to fulfill the mandates already established in federal laws and policies at a national level. Research is needed to establish systems for identifying and replicating evidence-based programs so that effective services can be further developed and tested *en route* to national implementation to benefit young children with challenging behavior.

(4) Research is needed to establish effective policies with regard to federal and state funding and regulation of systems for screening, identification, referral, and supports and services for children with challenging behavior. For example, natural variations in current policies can be evaluated through careful research to discover which approaches (or components of approaches) are most useful for helping young children with challenging behavior. Further research is needed to assess the degree of implementation of current policies designed to help young children with challenging behavior including research to obtain information from families with children with challenging behavior concerning their experiences in seeking help in order to develop screening,

referral, and access processes that meet the needs and preferences of families, including families from different ethnic and cultural backgrounds.

Pathways to Service Utilization: A Synthesis of Evidence Relevant to Young Children with Challenging Behavior

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Introduction

This document presents a synthesis of current knowledge pertaining to the utilization of services by young children with challenging behaviors and their families. The document was prepared by the Center for Evidence-based Practice: Young Children with Challenging Behaviors, a national research center funded by the Office of Special Education Programs of the U.S. Department of Education. The Center's goals are to: (1) identify and describe the current state of knowledge pertaining to evidence-based practices for young children with challenging behavior, (2) promote widespread awareness and adoption of these practices, and (3) add to the base of practical knowledge through a program of applied research. This synthesis document constitutes part of the Center's efforts to achieve the first of these goals. Parallel syntheses are being prepared in the areas of systems of service delivery and effective intervention practices for young children and their families.

The purpose of the synthesis is to present a concise picture of the state of empirical knowledge relating to the identification, screening, referral, and entry into service systems for young children with challenging behaviors. This picture is intended to convey the nature of what is known about service utilization and, also, to identify the most conspicuous gaps in current knowledge. The delineation of gaps should then inform the field about prominent needs to be addressed by applied research.

The approach used to develop the synthesis involved a focused process of information gathering with input from Center personnel as well as authorities from multiple disciplines including health and medicine, infant and child mental health, child care, child welfare, and education. The input obtained from national authorities included recommendations regarding the definition of service utilization, the location of pertinent resources, and the specification of bibliographic entries. As input was received, a core team of authors from the Center then integrated the information, distilled the significant knowledge that emerged from the synthesis, and summarized the knowledge and the most obvious gaps.

This document is a work in progress. It will be updated periodically and it will be submitted to leading authorities and professional organizations for evaluative review and revision. As the document is reviewed, the content will be prepared for dissemination in various formats to help inform the diversity of stakeholders concerned with young children with challenging behaviors.

Definition of Terms

Some terms were defined prior to undertaking this synthesis. They include:

Challenging Behavior: The synthesis used the definition adopted by the Center. This definition states that challenging behavior is any repeated pattern of behavior, or perception of behavior, that interferes with or is at risk of interfering with optimal learning or engagement in pro-social interactions with peers and adults. Challenging behavior is thus defined on the basis of its effects. While some children’s challenging behaviors are developmentally normative and effectively addressed by adult vigilance and the use of appropriate guidance procedures, the Center is focused on identifying evidence-based practices that prevent and/or address challenging behaviors that are persistent or unresponsive to those approaches. Common topographies of those behaviors include prolonged tantrums, physical and verbal aggression, disruptive vocal and motor responding (e.g., screaming, stereotypy), property destruction, self-injury, noncompliance, and withdrawal.

Young Children: For the purposes of the Center and the synthesis, “young children” was defined as the entire population of children between the ages of 0 and 6.

System: A system is defined as a perceived whole whose elements “hang together” because they continually affect each other over time and operate toward a common purpose.

Service system: A system of programs/resources/policies/services (federal, state, local, program level) that impact positively on children’s social-emotional development and behavior (e.g., an early childhood program that uses Medicaid, local mental health services, and provides a parent program to address children’s social-emotional development and behavior).

Evidence Base: The type of evidence that supports the efficacy and generality of a practice as indicated by evaluation research. Evidence may take various forms and may include experimental, qualitative, and descriptive data culled from a wide range of research or evaluation designs.

Types of Evidence

The data base on service utilization is sparse and there is essentially no experimental research available to compare and contrast different approaches to identification, screening, referral or access to service. Therefore, this synthesis was constructed from a variety of types of evidence (quantitative or qualitative) published in peer-reviewed journals and derived from single subject research, between group experiments, case studies, qualitative interviews, and participant observations. We also accepted as evidence data from internal and external evaluation reports, and survey and descriptive research including reports of population statistics accompanied by evidence of validity in data collection.

Procedures

As indicated previously, the authors relied on a number of sources to obtain primary and secondary sources of evidence related to service utilization. Authorities were asked for sources of relevant information via e-mail, telephone, and face-to-face contact; searches were conducted on the world wide web; and the published literature was surveyed with the assistance of databases in the fields of medicine, psychology, child development and education.

While the topic of the synthesis addresses the utilization of services for the challenging behavior of young children, there is essentially no information about service systems that focuses on challenging behaviors *per se*. Therefore, the synthesis includes information pertinent to a considerably broader purview. In many instances, the authors sought evidence relevant to the identification and subsequent service utilization of young children with mental health needs. The process of identification and screening, of course, could include large numbers of children who would *not* be identified as having mental health concerns or challenging behaviors so, in this respect, the relevant evidence base could involve very large populations of children eligible for screening.

The focus of the synthesis is on national processes relevant to the functioning of systems in health, mental health, child welfare, child care and education. The majority of the evidence cited is in the form of descriptive statistics documenting prevalence, patterns of child identification and utilization of services within these systems. We acknowledge that there is a great deal of knowledge that is not included in this synthesis that has been generated by model programs and local community innovations in and across all of the relevant systems.

Outline

This synthesis document is organized in the following manner. First, a description of the **intended pathways to service utilization** is presented, with an overview of national laws and policy governing the systems of health care, early care and education (with associated education services), child welfare, mental health, and early intervention and education. This section includes a table depicting the primary pathways associated with each service system. Second is a brief presentation of **knowledge related to the prevalence** of young children involved with each system. The third section presents the **current state of knowledge** in the areas of screening and identification and service utilization. The document concludes with some **summary statements**, conclusions, and a description of conspicuous gaps in our knowledge with an emphasis on which gaps should be most urgently addressed through a program of applied research.

Intended Pathways to Service Utilization: National Law and Policy

Prior to considering the current state of evidence regarding the identification of children with challenging behaviors, and their access to services, it is useful to examine the pathways that are intended and recommended by national law and policy. Table 1 presents an overview of the pathways to service utilization for young children with challenging behavior. In this section, we review the intended pathways in the systems of health care, early child care and education, child welfare, mental health, and early intervention and education for children with disabilities.

-- TABLE 1 ABOUT HERE --

Health Care

The health care system is a primary gateway for identification, screening, referral, and access to services for young children with challenging behavior. Thus, access to health care and the practices of pediatricians are extremely important elements in determining whether a child receives services. Three federal programs facilitate access to health insurance for low-income young children: Medicaid, the State Children's Health Insurance Program, and the Maternal and Child Health block grant program. Additionally, the American Academy of Pediatrics has developed a policy on Developmental Surveillance and Screening of Infants and Young Children.

Medicaid was established in 1965 as part of Title XIX of the Social Security Act and is funded jointly by the federal and state governments. As shown in Table 1, it is administered by the Centers for Medicare and Medicaid Services (CMS, formerly the Health Care Financing Administration). Within guidelines established by the federal government states have broad latitude in determining eligibility standards, delivery mechanisms, and the type, amount, duration and scope of services (Cavanaugh, Lippitt, & Moyo, 2000). Thus programs vary widely from state to state.

Federal law mandates that children under age six in families at or below 133% of federal poverty level (FPL), recipients of Supplemental Security Income (SSI), and children who are recipients of Title IV adoption or foster care assistance must be covered by Medicaid. Under federal guidelines, optional groups that states may choose to cover include infants up to one year of age with family income at or below 185% of FPL and "medically needy" persons. The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 gave states the option of covering legal resident aliens entering the United States before August 1996; those entering after that date are ineligible for coverage for five years. Children receiving Title IV-E foster care assistance are automatically eligible for Medicaid (Dicker, Gordon, & Knitzer, 2001). In 1998, nearly 37% of children ages 0-5 were enrolled in Medicaid (U.S. General Accounting Office [USGAO], 2001).

Federally mandated services under Medicaid include pediatric and nurse-practitioner services; rehabilitation services; and, most notably, Early and Periodic Screening, Diagnostic and

Treatment (EPSDT) services. In addition states may request waivers to pay for home and community-based services.

EPSDT was established as a Medicaid benefit in 1967 and expanded through amendments to the law in 1989. The goal of EPSDT is to provide comprehensive and preventive health care, *including behavioral health care*, to children under 21 years of age. States must cover any medically necessary services identified through EPSDT screenings that are part of federally mandated or optional services, whether or not the services are part of the state plan (Hoffman, Kless, & Curtis, 2001). Additionally, states are mandated to do outreach and case finding within 60 days of Medicaid eligibility determination and to provide facilitating services including transportation, case management, translation and appointment scheduling assistance (Cavanaugh et al., 2000). Health education, counseling and anticipatory guidance for parents is also required. States must establish screening schedules that conform to reasonable standards of medical practice and screenings must include a developmental history and a mental health assessment. In addition, interperiodic assessments for specific problems may occur at the request of families and may be performed by a mental health provider (Bazelon Center for Mental Health Law, 1999a). When a screening indicates the need for further evaluation, referral for complete diagnostic testing or assessment must be made without delay and include follow-up to ensure it occurred. The array of *behavioral health services* to which children are entitled includes inpatient and residential treatment, outpatient treatment by licensed professionals, rehabilitation services, targeted case management (assistance to gain access to needed medical, social, educational and other services) and, subject to federal waiver, home- and community-based services (Bazelon Center for Mental Health Law, 1999b). States are required to develop quality assurance procedures to ensure that comprehensive care is provided under EPSDT (CMS, 2002b). Thus as designed, the EPSDT program is meant to provide an accessible and seamless pathway to comprehensive preventive and remedial behavioral health services for Medicaid eligible children.

The **State Children's Health Insurance Program (CHIP)**, administered by CMS, was established in 1997 as Title XXI of the Social Security Act. CHIP grants federal funds to states to provide health insurance to low-income children not covered by other insurance. States may elect to expand Medicaid coverage using CHIP funds, create or expand a state program, or use a combination of these approaches. States are allowed to implement cost sharing, premiums, and deductibles for any services except pediatric preventive care including immunizations.

Children in families up to 200% of FPL (or up to 50% above current state Medicaid eligibility levels for those states with Medicaid eligibility above 150% of FPL) can be served by the program, although states can elect to serve a narrower group of children. Legal alien children are ineligible for coverage through non-Medicaid CHIP programs, but may be served by CHIP-expanded Medicaid programs if they resided in the United States prior to August 1996.

When CHIP funding is used to expand Medicaid eligibility, states must offer the full Medicaid benefits package including EPSDT, thus creating an entitlement for these newly

covered children. Non-Medicaid programs created with CHIP funding are not required to include EPSDT services, but must provide service packages that match one of six specified benefit packages. Currently, 16 states and territories have implemented separate state child health plans, 21 have implemented Medicaid expansions, and 19 have implemented combination plans (CMS, 2002c).

Outreach and enrollment services are CHIP mandates, but only 10% of funds can be used for administration and outreach. In the first years of the program, states had difficulty reaching enrollment targets (Cavanaugh et al., 2000; CMS, 2000b). However, between FY 2000 and FY 2001, enrollment grew by 38% to a total of 4.6 million children. CMS attributes this increase to state coverage expansions, program maturity and streamlined and simplified enrollment procedures (CMS, 2002d).

Title V of the Social Security Act authorizes the **Maternal and Child Health Block Grant** (MCHBG) program administered by the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA), U.S. Department of Health and Human Services (see Table 1). Formula Block Grants under Title V require a \$3 state match for every \$4 of federal money, and are given to states to improve the health of all mothers and children and promote the development of local systems of health care for children and pregnant women. In most states, Formula Block Grants are located within the state health department. Specific goals of the program include ensuring access to quality health care for all mothers and children (especially those with low income or limited availability to services) and for children with special health care needs, reducing infant mortality and the incidence of preventable diseases and handicapping conditions among children, increasing the number of low income children receiving health assessments and follow-up diagnostic and treatment services, providing preventive and primary care services for children and adolescents, providing comprehensive prenatal care, reducing adolescent pregnancy, preventing injury and violence, and putting into community practice national standards and guidelines. Allowable activities include infrastructure building services such as needs assessments, policy development, and training; population-based services such as newborn screening, outreach/public education and immunization; enabling services such as transportation, translation, health education, family support services, purchase of health insurance, and case management; and direct health care services.

Thirty percent of federal MCHBG funds must be used to provide preventive and primary care services to children (MCHB, n.d.a; MCHB, n.d. b). An additional 30% of the funds must be used for children with special health care needs which includes all children who have, or are at increased risk for, chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally. Key system outcomes identified by the Division of Services for Children with Special Health Needs (DSCSHN) include a medical home and health insurance for all eligible children, early and continuous screening, easy access to services, and partnering with families (MCHB, n.d. c). Which children qualify for services under this program and the specific services provided

are determined by state laws and regulations. While children with behavioral and emotional conditions are eligible under federal definitions, few states include these conditions in their eligibility definitions (Johnson, Knitzer & Kaufmann, 2002).

The Block Grant program also includes Special Projects of Regional and National Significance (SPRANS) and the Community Integrated Services Systems Grants (CISS). Both of these are competitive grant programs awarded to a variety of organizations. SPRANS includes research and training activities as well as projects implementing innovative strategies in maternal and child health. Johnson et al. (2002) report that Indiana has used a SPRANS grant to strengthen the focus on infant and toddler mental health within the Part C system through training and mentoring. CISS provides funding for the development and expansion of service delivery systems that integrate health, education and social services at the community level. (MCHB, n.d. d)

In conjunction with Medicaid and other federal programs, MCHBG programs must provide outreach to families to help them access services. Most MCHBG programs also work closely with Medicaid in providing services to children with special health care needs and in administering the EPSDT program (Cavanaugh et al, 2000).

American Academy of Pediatrics Policy Statement on Developmental Surveillance and Screening of Infants and Young Children. The American Academy of Pediatrics policy statement on Developmental Surveillance and Screening of Infants and Young Children was adopted in July 2001 (American Academy of Pediatrics, Committee on Children with Disabilities, 2001). It discusses the role of pediatricians in the early identification of developmental delays and referral of families to services. The statement notes that under the Individuals with Disabilities Education Act (IDEA), physicians are required to refer children with suspected developmental delays in a timely manner to the local early intervention system.

The policy cites a definition of developmental surveillance as “a flexible, continuous process whereby knowledgeable professionals perform skilled observations of children during the provision of health care. The components of developmental surveillance including eliciting and attending to parental concerns, obtaining a relevant developmental history, and making accurate and informative observations of children and sharing opinions and concerns with other relevant professionals.” (p 192).

In addition, the policy discusses the complexities involved in developmental screening of young children along with the evidence base and the advantages and disadvantages of using standardized, individually administered screening tools as opposed to parent report tools or systematic questioning of parents about developmental concerns. The policy notes: “Screening for behavioral and psychosocial problems in young children poses particular challenges...Many developmental screening instruments for young children do not address these areas adequately. Asking specific questions is most important.” (p 194) Several instruments that do detect behavioral concerns are listed. The policy lists nine specific recommendations pertaining to the

practice of pediatricians in maintaining knowledge of developmental and risk factors, acquiring skills and conducting valid screenings, interacting with families in a respectful and culturally-competent manner, and maintaining information about community resources to be able to make the most useful and appropriate referrals for services.

Early Care and Education

Because large numbers of young children spend time in out-of-home care arrangements, these settings provide important opportunities for identifying children with challenging behavior and forming connections to services. Federally supported early care and education programs include Head Start, Early Head Start, and the Child Care and Development Fund (CCDF).

Head Start and Early Head Start. Head Start was created in 1964 as part of the federal Economic Opportunity Act and is designed to be a comprehensive child development program serving low-income preschool age children. The overall goal of Head Start is to increase the social competence of young children. Head Start Performance Standards define social competence as the child's everyday effectiveness in dealing with both his or her present environment and later responsibilities in school and life (Administration on Children and Families [ACF], 2002b). Children in families at or below the federal poverty level are eligible for Head Start. In addition, 10 % of the children in each program may be children with disabilities, regardless of family income, and 10 % may be children from families that exceed the low-income guidelines but who meet local program selection criteria and would benefit from the program. The Head Start program includes health, dental and nutrition services; an educational program delivered primarily within classroom settings; parent involvement and social services; and child health and developmental services.

Early Head Start was established in 1994 to extend the Head Start concept to children from birth through three years. It is designed to provide a broad array of services to low income infants and toddlers, and like Head Start, emphasizes partnerships with families. Eligibility criteria are the same as for Head Start (income below federal poverty level). Services can be delivered in the home, in family childcare homes or in a center-based setting.

Head Start and Early Head Start are housed within the Head Start Bureau, Administration for Children and Families, Department of Health and Human Services (see Table 1). Head Start Performance Standards (ACF, 2002b) provide directives that encompass developmental and behavioral screening, and the provision of disability and mental health services to children in Head Start and Early Head Start.

The Child Health and Developmental Services sections of the Performance Standards cover screening, follow-up, and treatment. Screening standards specify that within 45 days of enrollment, a screening must be obtained or performed "to identify concerns regarding a child's developmental, sensory (visual and auditory), behavioral, motor, language, social, cognitive, perceptual, and emotional skills" (p 47). The screening must be linguistically and age

appropriate, sensitive to the child's cultural background, and must "utilize multiple sources of information on all aspects of each child's development and behavior, including input from family members, teachers, and other relevant staff who are familiar with the child's typical behavior" (p 48). Programs must obtain "direct guidance from a mental health or child development professional on how to use the findings to address identified needs" (p 48). These professionals are to advise staff on how to make timely referrals for comprehensive assessments by qualified professionals and assist staff in addressing children's identified needs within the program. Performance Standards also require ongoing procedures for identifying developmental concerns including emotional and behavioral concerns.

For children who have an "observable, known or suspected health or developmental problem" (p. 45), the program must arrange further diagnostic testing, examination and treatment and develop a follow-up plan. Involvement with IDEA's Part C and Part B programs are mandated for these children. Infants and toddlers suspected of having a disability must be referred promptly to the local Part C agency for eligibility determination. Three- to 5-year old children suspected of having a disability are to be referred to the local Part B agency for eligibility determination. For children with identified disabilities who are receiving Part C or Part B services, Head Start programs must assist with providing services specified in the Individualized Education Program (IEP) or the Individualized Family Service Plan (IFSP). Program staff must also support effective transition for children who at age three need to be considered for Part B services.

Performance Standard sections addressing mental health services specify that programs must secure the services of mental health professionals to ensure timely and effective intervention in mental health concerns. Mental health professionals, program staff, and parents must be involved in a regular schedule of on-site mental health consultation to design and implement program practices that respond to the identified behavioral and mental health concerns of an individual child or group of children; to promote children's mental wellness by providing group and individual staff and parent education on mental health issues; to assist in providing special help for children with atypical behavior or development; and to utilize other community mental health resources, as needed. Guidance to programs provided by ACF states that programs can support parent participation in mental health interventions through attending a first meeting with the mental health provider and parent, locating transportation or child care, and finding assistance to pay for interventions. It is also suggested that mental health consultants should make referrals to appropriate community mental health services and train program staff in making referrals and system navigation. Further, mental health consultants should act as liaisons between community agencies and the program, and should act as advocates for the child and family. For children with identified disabilities, mental health consultants are to assist parent and staff in accessing community agencies and ensure that the IEP or IFSP is properly implemented.

Just as all Head Start activities and services are family-centered, mental health performance standards call for programs to work collaboratively with parents by soliciting

parental information, observations, and concerns about their children's mental health; discussing and identifying with parents appropriate responses to their child's behavior; helping parents to better understand mental health issues; and supporting parents' participation in any needed mental health interventions.

As set forth in program performance standards, Head Start screening and mental health procedures should ensure timely identification, assessment and intervention in children's behavioral concerns, with intense family involvement in each step of the process.

Child Care and Development Fund (CCDF). In 1996, federal child care programs were consolidated into the CCDF, administered by the Child Care Bureau, Administration for Children and Families, DHHS (ACF, 2002f). As set forth in the Personal Responsibility and Work Opportunity Act of 1996, this funding is distributed to states to subsidize child care for low income working families and requires a state match and sliding fee scale. Children under age 13 who live in families at or below 85% of the state's median income are eligible if their parents are working, are transitioning off of public assistance, or are at risk of requiring public assistance. Very low-income families, children with special needs, and children in need of protective services receive priority. Child care centers and family child care providers who meet state and local licensing regulations are eligible to receive funds, as are relative caregivers. Federal regulations do not set quality standards for providers receiving funds through this program, nor do they require any type of developmental screening for children (ACF, 1998). States have broad latitude to set quality standards, eligibility requirements, reimbursement rates, and administrative procedures (Cavanaugh et al., 2000).

Title I Preschool Programs. Title I, Part A of the Elementary and Secondary Education Act provides federal funds to improve the education of low-income children including children ages birth through five (Cavanaugh et al., 2000). The U. S. General Accounting Office (2000) reports that in 1999-2000, 17% of school districts receiving Title 1 funds directed money to preschool programs, serving an estimated total of 315,000 children. Preschool programs funded by Title I must meet Head Start educational performance standards. Districts may use funds to establish preschool programs, or to extend or supplement services such as parent involvement, parent education and social services provided by other early childhood development programs, including Head Start (USGAO, 2000).

State Prekindergarten Programs. While Prekindergarten programs are established and funded by states rather than the federal government, they serve a substantial number of young children and thus are an important potential access point for screening and referral to services. According to Quality Counts 2002: Building Blocks for Success (Education Week, 2002), 39 states and the District of Columbia provide state-financed prekindergarten for some 3-5 year old children. Prekindergarten programs may be delivered through public schools, community-based child care, or Head Start programs; they vary in numbers and ages of children served, intensity, and quality standards (Mitchell, 2001). In 2001, the Erikson Institute (Horton & Bowman, n.d.) surveyed state-funded prekindergarten programs concerning assessment procedures. They found

that 14 states mandate developmental screenings in their prekindergarten programs and 2 other states commonly use such screenings.

Child Welfare

Child welfare encompasses protective services, family reunification, foster care, and adoption. While each state has its own child welfare system funded and administered by the state, approximately 45 % of the funding for state systems comes from the federal government (Bess, Leos-Urbel, & Geen, 2001). There are six major federal programs that provide funding to states for child welfare; all six are administered through the Administration for Children and Families, DHHS (see Table 1). The first four programs are authorized by the Social Security Act.

* Social Security Act (SSA), Title IV-B, Part 1, Child Welfare Services Program provides funds for services to prevent abuse and neglect, reduce foster care placements, reunite families, arrange adoption, and ensure adequate foster care. Under federal law, these funds may be used for child abuse prevention and for mental health treatment and intervention services for abused and neglected children. However, because of demand, these funds are most often used to support state child abuse screening and investigations systems (Cavanaugh et al., 2000).

* SSA Title IV-B, Part 2, Promoting Safe and Stable Families was passed in 1993 with the intent of providing a funding stream dedicated to prevention services (Cavanaugh et al., 2000). Allowable uses of funds are for services that support families at risk or in crisis, avert foster care, reunify families, and promote adoption (Bess et al., 2001). Specific services may include information and referral for families, early developmental screening for children, home visiting, parent education, and intervention for early behavior and adjustment problems (Cavanaugh et al., 2000). There are no federally mandated eligibility requirements for Part 1 or Part 2 of Title IV-B.

* SSA Title IV-E Foster Care and Adoption Assistance provides funds for out-of-home placement of low income children and adoption of low income and special needs children, including children with behavior problems (Cavanaugh et al., 2000). These fund may be used for foster care recruiting, licensing, placement services, case management and direct payments to foster families; and for adoption payments and placement, but are not authorized for use in mental health treatment. As an incentive to decrease the time that children spend in foster care, within certain limits states may transfer unspent IV-E funds to IV-B for use in child welfare, family preservation, and family support services (Cavanaugh et al., 2000).

* SSA, Title XX, Social Services Block Grant provides money to states for social services to low income families. States may use these funds for a wide range of services including mental health treatment and counseling; in recent years the most frequent uses have been for child care, child protection, and home-based services (Cavanaugh et al., 2000).

* The Child Abuse Prevention and Treatment Act [CAPTA, P.L. 93-247] provides funds to improve child protective service systems and to establish community-based family resource and support programs (ACF, n.d.a). CAPTA funds may be spent on prevention, case management, and mental health treatment services, with emphasis on service integration across systems, and coordination of resources. Title II of CAPTA specifically targets comprehensive family support and parenting education for parents of young children and families of children with disabilities (Cavanaugh, et al., 2000).

* Adoption and Safe Families Act [P.L. 105-89] enacted in 1997 stresses the health and safety of children in the child welfare system and requires greater emphasis on terminating parental rights, permanency planning, and adoption. While permissible uses of these funds include child screening, assessment, case management, and mental health treatment, the enacting laws and regulations contain no mandates for these services.

Mental Health

The Community Mental Health Services Block Grant Program (CMHSBG) [P.L. 102-321], administered through The Center for Mental Health Services, Substance Abuse and Mental Health Services Administration (see Table 1), awards grants to states for services to adults with serious mental disorders and children with serious emotional disturbance (SED). Under CHMSBG, children with SED are defined as: “persons: from birth up to age 18, who currently or at any time during the past year, have had a diagnosable mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified within DSM-III-R, that resulted in functional impairment which substantially interferes with or limits the child’s role or functioning in family, school, or community activities” (Center for Substance Abuse Treatment [CSAT], 1998, p 2). Mental disorders include any disorder listed in DSM-IV or their ICD-9-CM equivalent with the exception of developmental disorders and DSM-IV “V” codes such as parent-child problems unless they co-occur with another diagnosable serious emotional disturbance (CSAT, 1998).

The grants are designed to support existing public services and the development of systems of community-based care (Knowledge Exchange Network, 1999), however there is little regulation on how the funds are to be spent by states (Cavanaugh et al., 2000). Because of the competing demands on these funds and the requirement that they be used for children with severe emotional disturbance, very little of the money is spent on services for children under six years (Cavanaugh et al., 2000). CMHSBG does not mandate or set aside funds for prevention.

Early Intervention and Education for Children with Disabilities

The Individuals with Disabilities Education Act (IDEA) Part B program provides funding for special education and related services for preschoolers (ages 3-5 years) with disabilities while the Part C program provides funding for early intervention services for children birth-2 years with disabilities (see Table 1). While the law does mandate critical components to these

programs, states also have broad latitude in how they administer and implement the mandates and in determining outcomes and indicators (Cavanaugh et al., 2000; Meisels & Shonkoff, 2000).

Part C: Infants and Toddlers with Disabilities Program. The Part C program was established to: 1) enhance the development of infants and toddlers with disabilities and minimize their potential for developmental delay; 2) reduce education costs by minimizing the need for special education once children reach school age; 3) enhance the capacity of families to meet the special needs of their infants and toddlers with disabilities; and 4) enhance capacity to identify, evaluate and meet the needs of historically underrepresented populations, particularly minority, low-income, inner-city, and rural populations (Office of Special Education and Rehabilitation Services [OSERS], 1997; IDEA Practices, 1999). In addition, Part C mandates the creation of coordinated, comprehensive multi-disciplinary statewide system that includes outreach, early identification, screening, evaluation/assessment, referral, case management (Cavanaugh et al., 2000; Meisels & Shonkoff, 2000; OSERS, 1997) and the provision of services to eligible children and their families. Each state must designate a lead agency for Part C and these vary from state to state, with health, education, and human services/ social services the most common lead agencies (Trohanis, 2002). The systems developed by the states vary considerably in their organization, characteristics and operation (Hebbeler, Spiker, Wagner, Cameto & McKenna, 1999).

Part C includes eligible children from birth to their third birthday and their families. Once states choose to participate in Part C they must serve all eligible children and their families. All states are currently participating in Part C. Each state defines the criteria for developmental delay as long as eligibility includes children with delays in one or more areas. Social and emotional development is listed as one of the five developmental areas that early intervention services are meant to address. States must also provide services to children with diagnosed medical or physical conditions likely to cause a developmental delay and may also elect to serve children who are at-risk for developmental delay (IDEA Practices, 1999; OSERS, 1997).

Part C is designed to create a statewide early intervention system by drawing upon and coordinating existing resources funded through other local, state, federal, and private resources. Part C funds are designated as the payer of last resort and can only be used to pay for services not covered by another public or private source including Medicaid (IDEA Practices, 1999; OSERS, 1997). The law mandates that certain components that facilitate identification and access to services must be provided free of charge to families. These include: comprehensive child find and referral systems, public awareness programs, a central directory of services and resources, timely and comprehensive multidisciplinary evaluations of children's needs, individualized family service plans, service coordination (defined as an active, ongoing process that assists and enables families to access services) and support for transition to preschool or other appropriate services (National Early Childhood Technical Assistance System [NECTAS], n.d.). States may charge families for other services in accordance with provisions in the law and the parent's ability to pay.

The public awareness system must inform the public and parents about: 1) how to make referrals, 2) how to gain access to evaluation and other early intervention services; and 3) the central directory of services and resources. It must also include the dissemination of information for parents to hospitals and physicians and to other primary referral sources. (IDEA Practices, 1999).

The Child Find system is mandated to include policies and procedures for ensuring that all infants and toddlers who are eligible for services under Part C are identified, located, and evaluated. It must be coordinated with all similar state and local efforts including Part B, EPSDT, maternal and child health, Head Start, and developmental disabilities programs and must include procedures for primary referral sources (specified as hospitals, physicians, parents, day care programs, local education agencies, and other social service agencies and health care providers) to use in referring children as well as ensuring that referrals are made within two days of identification (IDEA Practices, 1999).

Part B: Preschool Grants for Children with Disabilities Program. The purpose of IDEA Part B, Section 619: Preschool Grants for Children with Disabilities Program is to provide funds to assist states in providing special education and related services to children ages three through five years with disabilities. At the state's discretion, they may also serve two year-old children with disabilities who turn three during the school year. To receive funding, states must have policies and procedures in place for ensuring the provision of a free and appropriate public education to all eligible three to five-year-old children. (OSERS, 1997). All states currently participate in the Preschool Grant program and receive these federal funds (Cavanaugh et al., 2000).

Part B of IDEA, the State Grant Program, specifies the requirements for serving children with disabilities from ages 3 through 21 years and thus applies to children eligible for services under the Preschool Grants Program. States must develop their own implementing policies and procedures that are consistent with Part B regulations, and some states have guidelines specifically covering preschool age children (Walsh, Smith, & Taylor, 2000). The federal regulations governing Part B contain few references to preschool children, however there are provisions regarding Child Find activities, eligibility, and transition of children receiving services under Part C into Part B services (IDEA Practices, 1999).

The child find provisions of the regulations governing Part B (IDEA Practices, 1999) require that states have policies and procedures in effect to ensure that all children with disabilities who are in need of special education and related services are identified located, and evaluated, including children attending private schools and highly mobile children, such as migrant and homeless children. States must also provide for coordination of Part B and Part C child find and evaluation activities including an interagency agreement specifying which lead agency will be responsible for infant and toddler child find and evaluation activities. The regulations specify that the transition for children receiving Part C services who are eligible for Part B preschool programs must be smooth and effective. However, the only specific provisions

are for an IEP or IFSP to be developed by the child's third birthday, and participation by the local education authority in a transition planning conference arranged by the Part C lead agency.

Evaluations under Part B regulations must be comprehensive enough to identify all needs for special education and related services, must use tools that are racially and culturally nondiscriminatory, must include information from parents, and include assessments in all areas related to the suspected disability including social and emotional status. To be eligible for services under Part B a child must be found to have one of thirteen specified disabilities, which includes emotional disturbance, and as a result need special education and related services. However, at state and local school district discretion, an additional category, children 3-9 years identified with a developmental delay in one or more areas including social or emotional development may be utilized. According to NECTAS (2001), 35 states are using developmental delay as an eligibility classification under Part B and 18 states have extended the age range for developmental delay beyond age 5. Local districts are not required to adopt their state policy on developmental delay (Division on Early Childhood [DEC], 2001). The Division for Early Childhood of the Council for Exceptional Children recommends that developmental delay be available for children from 3-9 years and that eligibility determination for developmental delay be based on authentic, developmentally appropriate, and ecologically valid assessment tools and practices rather than relying solely on traditional psychometric assessments and that informed team consensus should be the basis for decision-making (DEC, 2001).

Special education services may be provided to children within community settings such as Head Start, private preschools or child care centers when the IEP team determines this is the least restrictive environment appropriate to the child (Walsh et al., 2000). For children exhibiting challenging behavior who have already been determined eligible for Part B services, behavior must be considered and discussed as part of the IEP process.

Services for children under Part B are not dependent on the child's diagnosis or disability category, but are driven by the child's individual needs as determined by the IEP/IFSP Team and documented in the IEP/IFSP (DEC, 2001). All services listed in the IEP or IFSP, including special education and any related services, such as psychological services, counseling, parent counseling and training must be provided at no cost to the family. School districts are responsible for ensuring these services are provided. However, Part B funds are to be used to supplement Medicaid and other non-educational public and private funding sources. Interagency agreements or other mechanisms defining financial responsibility must be developed in each state.

Overview of Prevalence Research

Studies of the rates at which behavior problems occur in young children have used a wide variety of methodologies, instruments and populations. Thus it is not surprising that the studies have resulted in a range of prevalence estimates.

Several studies have examined prevalence rates in samples of children presenting for healthcare visits. Lavigne et al. (1996) studied prevalence rates for emotional and behavioral problems in 3860 two- to five-year-old children identified through pediatric visits. The sample was 67% white and 19% African-American, with the majority from lower socioeconomic groups. Results showed that 21.4% of the children met criteria for a DSM-III-R Axis I disorder, with 9.1% of children classified as severe. Oppositional defiant disorder (ODD) was by far the most common disorder, present in 16.8% of the children; of these cases, 8.1% were rated severe and about 25% of the cases were comorbid with another diagnosis. Boys were almost twice as likely as girls to receive a diagnosis of ODD. Attention-deficit hyperactivity disorder (ADHD) was found in 2% of the sample and was almost always comorbid with another disorder, usually ODD. Prevalence rates for each of the Emotional Disorders (e.g. avoidant disorder, separation anxiety disorder, overanxious disorder, depression) were less than 1%. In the V code category, the prevalence of parent-child problems was 4.6%. A significant increase in disorder across all levels of severity occurred between ages 2 and 3 years then showed slight declines at ages 4 and 5 years.

In this same study, 8.3% of the children scored above the 90th percentile on the Child Behavior Checklist (CBCL) Total Behavior Problems Scale. The rates for externalizing disorders and internalizing disorders were both 3.7% and the rate for comorbid disorders was 3.3%. There were no sex differences for internalizing problems, but significantly more boys showed externalizing problems, total behavior problems, and comorbid disorders. The authors speculate that the discrepancy between the findings for the two classification systems may be due to false-negatives on the CBCL.

Two studies have used the Pediatric Symptom Checklist (PSC), a parent report measure, to screen for psychosocial problems at pediatric visits. Both studies reported overall problem rates without distinguishing between externalizing and internalizing problems. Jellink et al. (1999) used the PSC to screen 5573 four- and five-year old children and found a prevalence rate of 10% for psychosocial dysfunction using a cut-off score of 24. The sample was 80% white and 21% Medicaid eligible. Poverty, single-parent family, and a history of mental health treatment were significantly related to higher levels of impairment. Scores were 1 ½ points higher for boys than for girls.

Navon, Nelson, Pagano, & Murphy (2001) examined the use of the PSC in a sample of 297 children ages two through five being served by pediatricians in a large city health maintenance organization whose membership was 85% Medicaid enrolled. They report that 23% of the sample received a positive score (24+ for 2 and 3 year old children, 28+ for 4 and 5 year old children), indicative of moderate to severe problems. Based on follow-up interviews and scores on the Preschool and Early Childhood Functional Assessment Scale (PECFAS) with a sub-sample, the authors estimate the prevalence of behavioral health problems at 19% in the preschool population.

Two studies have looked at rates of behavior problems in children entering kindergarten. The Early Childhood Longitudinal Study, Kindergarten Class of 1998-99 is following a nationally representative sample of 22,000 kindergarten children. Teacher ratings of children entering kindergarten showed that 11% argue with others, 8% fight with others, and 10% easily get angry, often or very often (West, Denton, & Reaney, 2000). These ratings changed very little between fall and spring of the Kindergarten year. Pianta and Caldwell (1990) used the Teacher-Child Rating Scale on a sample of 325 children entering kindergarten. They found prevalence rates of 25% for moderate externalizing behavior problems, with almost twice as many boys as girls falling into this category. No demographic information other than maternal education was provided for the sample: 61% of the mothers had 12 or more years of education.

In a study of the Early Screening Project (ESP), Feil, Severson, and Walker (1998) screened 2797 children ages 2.4 to 6 years enrolled in preschool, Head Start and kindergarten programs in nine states. The children were evenly divided between middle and low income families. The percentages of children whose scores exceeded one standard deviation from the mean on the four measures used in Stage 2 of the ESP, and thus considered “at-risk” were 6% of boys and 1.9% of girls for externalizing behavior and 3.6% of boys and 3.2% of girls on internalizing behavior. Stage 3 of the system identifies children whose observed behavior in classroom settings exceeds one standard deviation from the mean. These children are considered candidates for further assessment and, if indicated, pre-referral intervention. In the current study, .8% of males and .5% of girls met Stage 3 criteria for externalizing behavior, and .3% of boys and .6% of girls met Stage 3 criteria for internalizing behavior.

Studies that have examined behavior problems rates in the Head Start population include Webster-Stratton and Hammond (1998) who found that in a group of 426 four-year old Head Start children, 23% scored in the clinical range on the Eyberg Child Behavior Inventory and 22% scored in the clinical range on the CBCL externalizing scale; both instruments used parent report. Observations conducted in the children’s homes showed that the children exhibited noncompliant, oppositional and aggressive behaviors at a mean rate of 13 per 30 minute period, with 30% exhibiting rates in the moderate to high categories. On the Teacher Report of Conduct Problems, 15% of the children scored above the cut-off for externalizing problems and 8% scored in the clinical range; 20% scored in the high range for angry-aggressive behavior on the Teacher Preschool Socio-Affective Profile. Classroom observations found that 11% of the children scored in the high range for physical aggression (3 or more events in one hour), 7% scored high on noncompliance (3 or more events in one hour), and 31% scored high on disruptive behavior (6 or more events in one hour). The authors also looked at pervasiveness of behavior problems and found that 45% of the children had problems at either home or school, 19% showed problems in both settings, and 36% displayed normal conduct in both settings.

Kaiser, Hancock, Cai, Foster, and Hester (2000) looked at parent report CBCL/2-3 scores for 259 three-year old Head Start children. Twenty-one percent of boys scored in the clinical range on the total problem scale and the same percentage of boys were in the clinical range on the externalizing behavior scale. A higher percentage of boys (26%) scored in the clinical level

on the internalizing behavior scale. For girls, 16% were in the clinical range for total problems, 13% for externalizing behavior and 24% for internalizing behavior. The authors report that their sample scored higher than the normative sample for the CBCL/2-3, but lower than the clinic-referred sample.

Kupersmidt, Bryant, and Willoughby (2000) examined rates of aggressive behaviors through classroom observations in 440 children in Head Start programs and 131 children in community childcare settings. They found no significant differences in person prevalence rates of aggression between the two groups, with about 10% of the children in both populations exhibiting antisocial aggressive acts an average of once a day or more. Head Start children exhibited higher levels of physical aggression than the community childcare children, but children in childcare showed higher rates of verbal aggression. Boys demonstrated higher levels of aggression than girls.

Kelleher, et al., (2000) examined changes in patterns of referrals for pediatric visits from 1976-1996 analyzing hospital records (N = 9,612 for 1976 and 21,065 for 1996). The identifying factor was clinician-identified “psychosocial problems” from age 4 to 15. Rates changed from 6.8% of sample in 1976 to 18.7% in 1996. Increases were found in all diagnostic categories except MR. The largest increases were in attention disorders (1.4% - 9.2%). Referrals for medication related to ADHD increased from 32% (of that category) to 78%. The authors attributed the pattern increases to the correlated increase in incidence of single parent families identified from Medicaid enrollment (poverty).

In summary, for samples of young children identified through healthcare visits, estimates of psychosocial problem rates are between 10% and 21%, while rates for externalizing problems are between 7% and 17%. Within kindergarten and preschool populations, rates of 8% to 25% for externalizing behavior problems have been found. For Head Start children, estimated prevalence rates vary from 10% to 23% for externalizing behaviors. These estimates have a somewhat higher upper range than that estimated by Campbell (1995) in her review of prevalence studies of behavior problems in young children which concluded that “roughly 10-15% of preschool children have mild to moderate problems” (p. 117).

No studies of prevalence rates for disorders in community samples of children under two years of age were found. This may well be due to the evolving nature of classification systems of infant disorders and the problems inherent to such systems, including the rapid development rates of infants, their inability to report their own experience and their more limited repertoire of behavior compared to older children (Zeanah & Boris, 2000).

The Knowledge Base of Service Utilization for Young Children with Challenging Behavior

In the previous sections we have provided overviews of the intended pathways to service utilization (through a summary of pertinent national laws and policies) and research relating to prevalence. The following section offers a summary and synthesis of existing knowledge related

to the pathways to service utilization for young children with challenging behavior. This section is designed to present the results of planned research and systematic data collection regarding what we know about service utilization. We begin with a summary of knowledge pertaining to screening and identification and service utilization. Within these sections, the knowledge is presented according to the pathways for the five superordinate systems of health care, early child care and education, child welfare, mental health and early intervention and education for children with disabilities. The synthesis is arranged by offering a concise statement of a notable “finding,” followed by a summary of the supporting documentation for each of these statements.

Knowledge Related to Screening and Identification

(1) Finding: Three federal programs providing health insurance coverage for children, provide important opportunities for the identification of children with challenging behavior.

In FY 1998, 9,222,363 children five years and under were enrolled in Medicaid (Tang, Siston, & Yudkowsky, 2000), representing 37% of the entire 0-5 population (USGAO, 2001).

In FY 2001, 1.1 million children ages five years and under were enrolled in SCHIP representing approximately 5% of the total 0-5 population (CMS, 2002d).

Programs funded by Maternal and Child Health block grants cover a broad range of activities and the number of children and families affected is not known.

(2) Finding: Medicaid screening and identification services are mandated for all eligible young children, including those with challenging behavior. However, fewer than 1/3 of the eligible children receive a full EPSDT screen and even fewer receive a screen that includes behavioral health.

Evidence indicates that many eligible children are not receiving EPSDT services. First, not all children eligible for Medicaid are enrolled. The Kaiser Commission on Medicaid and the Uninsured (2001) reports that in 1998, 16% of low income (>200% FPL) children were uninsured, and that 69% of these children were eligible for Medicaid.

Data collected by CMS and a number of smaller scale studies have indicated that many eligible children do not receive EPSDT screens. Data reported to CMS by the states for 1998 (CMS, 2000a), indicate that 79% of children under one year of age and 56% of 1-5 year old children received at least one screen during the year.

However, the U.S. General Accounting Office (2001) indicates that these state-reported data are highly unreliable, and cites smaller, more focused studies that show much lower rates for full EPSDT screenings including a study in Washington state that found rates of 32% for infants

(birth to 15 months) and 20% for 3-6 year olds under managed care plans, and rates of 7% for infants and 24% for 3-6 year old children under fee-for-service plans.

There are also indications that even when EPSDT screens are performed they do not always include a behavioral health screen. Pires, Stroul & Armstrong (2000), in their study of state Medicaid managed care reforms report that although 93% of the managed care reforms studied incorporated EPSDT, this had not resulted in earlier identification of behavioral health problems. This was attributed to disincentives for identifying problems, the time and cost involved in performing screenings, and screening tools that did not include mental health components.

(3) Finding: Pediatricians correctly identify and appropriately respond to only a small portion (estimates range from 17% to 40%) of young children with challenging behavior.

Riekert, Stancin, Palermo, & Drotar (1999) reviewed the findings from previous studies that found pediatricians correctly identified only 17% of the children with mental health problems and, of those identified, provided guidance or referral in only 40% of the cases. The barriers that have been identified include the reluctance of families to report concerns to the physician, time constraints during office visits that limit opportunities to observe child-adult interactions, lack of training concerning psychosocial problems, and limited availability of mental health professionals to implement psychological interventions.

Previous research has shown that 70 - 81% of the questions parents wanted to ask pediatricians concerned psychosocial issues. Given the importance of psychosocial issues, the nature of child health visits to physicians was explored by Sharp, Pantell, Murphy, & Lewis (1992). The authors analyzed videotapes of physicians during child health supervision visits. They found that in 88% of the visits physicians offered or parents took the opportunity to express psychosocial concerns to their physicians. Most often these centered on conduct/behavior problems, insecurity, social problems with family members, and learning difficulties. The physicians' responses to these problems consisted of ignoring (17%), asking for further information but providing no information (43%), reassurance (3%), psychosocial information or action (27%), medical information or action (3%), or some combination of psychosocial and medical information or action (7%). Thus, in 60% of the instances, the psychosocial issues were dropped while only 40% were responded to with reassurance, guidance, or referral.

Holden and Schuman (1995) reviewed the literature on detection of mental health problems and found that pediatricians clearly have a "less than optimal" sensitivity to mental health disorders. However, the pediatricians did seem to be able to detect cases when more severe impairment is present and when parents directly express their concerns about their child's behavioral and emotional problems. In spite of this, the authors estimated that nearly two-thirds of all mental health problems are undetected by primary care physicians. The authors called for further research regarding screening and identification and pointed to the need to include preschoolers who have been nearly omitted from previous research.

Of the children identified by Lavigne, et al. (1993) as having emotional-behavioral problems, the authors found that 25.9% had received counseling from the pediatrician, 3.4% had been treated with medication, and 19.0% had been referred to a mental health professional. The results were not associated with sex, race, or SES factors except that the psychologists found significantly more problems among the white 4 and 5 year olds compared to the physicians. SES and race also were not significant factors in a larger study of attentional and hyperactivity problems identified by primary care physicians (Wasserman, et al., 1999).

(4) Finding: Training and the use of special screening tools seems to improve the pediatricians ability to accurately screen for problems among young children with challenging behavior.

Erickson, Hill, & Siegel (2001) looked at facilitators and barriers to physicians use of screening tools. Their study was specifically designed to assess physicians use of domestic violence screening protocols but the issues seem to be the same for mental health problems of children with challenging behavior. The most commonly perceived barriers to screening were lack of education, office protocol, time, and support staff. For example, those pediatricians with training were 10.9 times more likely to screen. However, among those who did screen, lack of referral sources was cited as an additional barrier to screening.

To facilitate discussions of challenging behavior, a Pediatric Symptom Checklist was developed for use in primary care settings. The PSC is a one-page questionnaire completed by parents regarding their child's emotional and behavioral problems. Jellinek, Murphy, Little, Pagano, Comer, & Kelleher (1999) assessed the feasibility of using the PSC in a large national sample of pediatric offices. They found that 97% of the parents completed the PSC thus confirming the feasibility of using the PSC as a screening device. They found that 10% of the preschool children in the sample exceeded the cutoff score for "impairment." Poverty, single-parent family, and a history of mental health treatment were significantly related to higher levels of impairment, especially among boys.

Horowitz, Leaf, Leventhal, Forsyth, & Speechley (1992) had doctors complete a checklist of psychosocial and developmental problems for 1886 children ages 4-8 years at pediatric visits resulting in identification of 27% of the children with at least one psychosocial or developmental problem. Forty percent of the identified children received intervention by the pediatrician, 16% were referred to a specialist and 31% received no active intervention. Four factors were found to be associated with recognition of problems: well child as opposed to acute care visits, clinician reported knowing the child well, child was male, and child had unmarried parents.

(5) Finding: Significant barriers to identification and referral of young children with challenging behavior exist in the medical profession.

Gardner, Kelleher, Wasserman, Childs, Nutting, Lillienfeld, & Pajer (2000) reviewed data for over 21,000 children aged 4 – 15 years who had been seen by a pediatrician. They found that pediatricians tended to provide counseling for psychosocial problems more often when they had more time, when they perceived that the family agreed with the clinician’s assessment of the problem, and when the child exhibited the physical symptoms of a psychosocial problem. Pediatricians referred children to a specialist more often when the child had greater impairment (e.g., higher Pediatric Symptom Checklist score, lower Family Apgar score), when emotional problems were found, and when the pediatrician perceived that the family agreed with the clinician’s recommendations for treatment. Medications were prescribed more often for older children and for children with more persistent problems. The authors point to the key role that the parent-physician relationship plays in the mental health treatment options exercised for children with challenging behavior.

Navon, Nelson, Pagano, & Murphy (2001) looked at 570 children (297 younger than 6 years) who had been screened using the Pediatric Symptom Checklist. They found that 25% (23% of those under 6) had a positive score on the Checklist indicating problems ranging from moderate to severe. The authors followed up with a subsample of the children and found that fewer than one-third of the children with significant behavioral health problems were receiving needed services. The authors stated that barriers to receiving adequate mental health services included a shortage of existing services (caused in part by staff turnover and long waiting lists), inadequate follow-through on referrals by families, and a lack of awareness about (or availability of) needed behavioral health care resources in the primary care setting.

(6) Finding: “Model” programs exist that take a more proactive and evidence-based approach to screening and referral for preschool children with challenging behavior.

Some states have adopted a population-based screening and identification system. For example, the Hawaii Healthy Start Program uses a two-stage screening and assessment protocol for all live births in the state. First, the intake medical record is reviewed for risk factors and family stress factors. Then, using a cutoff score, the family is placed either in the “not at risk” category and no further work is done, or placed in an “at risk” category. At-risk families become eligible for the home visiting services offered by the state (Duggan, Windham, McFarlane, Fuddy, Rohde, Buchbinder, & Sia, 2000). Their goal is to determine the risk status for at least 90% of families of newborns within one week of birth and state funding is available to provide home visiting to about 40% of the at-risk families. Results of the study conducted by these authors found that 84% of the families of newborns were screened and 74% were screened within the one-week time limit set as a goal. With only 1% refusal-to-participate, the bulk of the remaining missed assessments were due to one hospital that used their own staff instead of specially trained early identification staff. Of the at-risk families offered home visiting services, 82% accepted. However, attrition reduced the families receiving home visiting services to 90% at 3-months old, 70% by 6 months, 56% by 9 months, and 49% at 12 months.

Bergman, Corbin, & Haber (1982) noted that previous research has found many inadequacies in referral processes available to primary care physicians. These include lack of trust by the parents in the physician, the receiving professional or agency did not feel the referral was appropriate, or the family's belief that the referral would not be helpful. To address these concerns, the authors established a behavioral evaluation and referral unit to facilitate the referral of children with challenging behavior as identified by the pediatrician. About 25% of all children seen by the pediatricians were evaluated by the behavioral evaluation and referral unit. The authors found that 84% of the families completed the referral (88% for the families with children 2 – 5 years old) and 60% received further evaluation and treatment for mental health problems. They attribute this success to the personal relationship established with families, the relationship established with referral agencies, and the availability of unit staff to serve as a bridge for the families from the clinic to the referral agency. There were no significant correlations between demographic or patient variables and completion of the referral.

(7) Finding: Large numbers of young children are served in early care and education programs that provide opportunities for screening and identification.

During the 2000-01 school year, 795,597 children were enrolled in prekindergarten programs based in public schools and 3,381,629 children were enrolled in kindergarten (U.S.DOE, NCES, 2002) providing links to IDEA screening and identification services.

In FY 2001, Head Start served 905,235 children (ACF, 2002e). While in the 1997-98 program year only .57% of Head Start children nationally were classified as having an emotional/behavioral disorder (Lopez et al., 2000), evidence indicates that within Head Start programs children are identified with emotional/behavioral concerns and receiving psychological consultation services at much higher rates (Mowder et al., 1993). In addition, 59% of Head Start children were enrolled in the Medicaid EPSDT program in FY 2001 (ACF, 2002g).

(8) Finding: Substantial numbers of young children are served in early care settings that may not provide systematic screening.

In FY 1999, 1,760,260 children were served in the subsidized child care program (CCDF/Child Care and Development Fund). This figure includes older children in after school care. (ACF, 2000).

Sixty-one percent of children younger than 3 years, and 37% of three- and four-year old children of working mothers are served in family child care, relative care, or by a nanny/babysitter (Capizzano, Adams & Sonenstein, 2000).

(9) Finding: Children with challenging behavior can be identified among those in preschool environments.

Feil, Walker and Severson (1995) studied the validity and reliability of the Early Screening Project (ESP), a multiple-gated screening system for detecting behavior problems in preschool children within classroom settings. They concluded that ESP provides a reliable, cost-effective and accurate screening procedure. In a further investigation of ESP, Feil, Severson and Walker (1998) assessed 2,797 preschoolers in 9 states and found significant differences between children referred for behavior problems and non-referred controls. They concluded that this procedure was valid, inexpensive, showed less bias toward boys and greater accuracy than other screening procedures.

(10) Finding: Biases may exist in identification and referral systems for young children with challenging behavior.

Fantuzzo, et al., (1999) reported two qualitative studies looking at 308 Head Start children referred for special needs using the Early Intervention Screening Profile (EISP). They concluded that EISP is biased in favor of identifying speech and language problems and against behavior problems. They conclude the reasons are linked to easy availability of speech/language services relative to behavior support services.

Sinclair (1993) evaluated 159 Head Start children referred from screenings for special services, of which 151 qualified for special education. The study identified four clusters of referral patterns. The most significant finding was that the categories of LD (26%) and SED (29%) greatly exceeded the OSEP figures estimated at 4%. At kindergarten entry, 25% of the children in the serious emotional disturbance cluster were referred to special education.

Forness et al. (1998) followed 4,161 Head Start children through first grade to examine patterns of referral to special education. The children were tested extensively by the researchers at kindergarten entry to determine if they met research diagnostic criteria for special education disability categories, with .32% of the children meeting diagnostic criteria for emotional disturbance. At the end of first grade, .95% of the sample had been identified by schools as emotionally disturbed, a rate considerably higher than the rate at which first graders are identified with emotional disturbance nationally. The findings also supported the concern that children with ED may be referred to other categories of special education (speech/language and learning disabilities). This concern was supported by additional results (Forness et al., 1998) examining special education referrals for the same cohort of children at the end of second grade.

Duncan, Forness and Hartsough (1995) used archival data to examine the diagnostic and treatment histories of 85 children with SED. For children with conduct disorders, a problem was first noticed by someone outside the family when the child was a mean age of 4 years 6 months, the first intervention occurred at a mean age of 5.4, the first IEP was developed at a mean age of 7.8 and day treatment placement occurred at mean age 10.3. For children with ADHD, the corresponding mean ages were 4.0, 5.0, 6.6, and 9.4. The authors conclude that these data raise concerns about the lack of early identification for children with disruptive behavior disorders.

Gresenz, Liu, & Sturm (1998) examined the service costs and utilization patterns of three groups of children (N=40,506 ages birth to 5 years, N=71,179 ages 6 to 12 years, and N=55,451 ages 13 to 17 years) compared to adults (N=434,515) in carved-out behavioral health care plans. Over a 12-month period, 0.76% of the children ages birth to 5 years used outpatient behavioral health services and none used inpatient services. This compares to 3.19% and 5.03% outpatient usage for the 6-12 and 13-17 year olds and 4.72% for the adults. Given the similar incidence rates for moderate to serious problems in all age groups (averaging around 10 – 15%) of children, it appears that the youngest children in this study were seriously underserved.

Tarnowski, et al., (1990) replicated an earlier study from 1978 examining patterns of referral rates for academic/behavior problems (222 children, mean age: 8.34 years). They found significantly higher referral rates to special education for children born in the summer months. Boys were referred at twice the rate of girls. The pattern was unchanged from 1978 and most of the referrals failed to result in special education placement.

(11) Finding: Many young children are served by state Child Welfare Systems.

In 1999, 200,320 children ages 0-3 years and 195,239 children ages 4-7 years were reported to state child protection systems and determined to have experienced or to have been at risk of experiencing abuse or neglect (ACF, 2001a). In the same year, there were an estimated 166,664 children ages 0-5 years in foster care (ACF, 2001b).

(12) Finding: Children placed in child welfare services often have a complex array of challenging behavior and consume a disproportionate share of resources devoted to the problems of young children.

Screening and identification practices in child welfare vary by state and are governed by state laws and departmental regulations. Typically, various forms of physical and emotional abuse, neglect or abandonment, inappropriate sexual contact, threats to development (e.g., alcohol or drug use by parents), and inability of parents to control their child are included as reasons for state intervention in family life. Screening is done by family members, physicians, teachers, neighbors, child care or mental health professionals and others who have contact with children. Assessment is then carried out by social workers or other professionals, often with judicial review and disposition as a final step. Children under the jurisdiction of child welfare automatically become eligible for Medicaid-funded screening, identification, and other services.

Attempts have been made to conceptualize a better system for assessment (e.g., Kates, Johnson, Rader, & Strieder, 1991) but, as Rosenfeld, et al., (1997) point out, many children's situations are exacerbated by the system they encounter and have special medical, psychological, educational, and social needs that most child welfare systems were not designed to address. Thus, better assessments may not lead to better services under the current state of affairs.

Children who have been removed from their families and placed in foster homes usually have a complex array of problems. For example, in California Halfon, Mendonca, & Berkowitz (1995) looked at 213 children in foster care. Their average age was 3 years and 85.4% were placed because of neglect or abandonment. A history of maternal drug use was present for 94% of the infants. Over 80% of the children had emotional, relational, and behavioral problems while 20% had growth abnormalities, 30% had neurological abnormalities, and 28.8 % had three or more medical conditions. Halfon, Berkowitz, & Klee (1992) found that foster children make up 4% of the Medicaid population in California and use nearly 50% of the Medicaid child mental health dollars, another indication of the complex issues presented by children in child welfare.

Marsenich (2002) reviewed the literature regarding mental health services for children in foster care. She concludes that high levels of cooperation are required between child welfare and children's mental health services because of the high level of mental health needs among foster children. The author found that substance abuse and poverty account for an increasing number of birth to 5 year old children entering the foster care system. By 1997, 33% of the children in out-of-home care in California were 5 or younger. The incidence of behavioral and emotional problems is three to six times greater among foster children than children in the community. Developmental delays among foster children ages 2 to 5 years range between 49% and 61% compared to prevalence figures of 3% to 18% in the general population. Mental health service utilization is high among foster children, with greater service usage for older children, males, children placed with non-relatives, those removed for physical or sexual abuse, and white children (also see Garland, Landsverk, Hough, & Ellis-MacLeod, 1996).

(13) Finding: Mental health systems for very young children are almost non-existent.

As Kaufmann & Wischmann (1999) point out, there is no cohesive national public policy for meeting the needs of young children with challenging behavior. Although some progress has been made in mental health screening (Loseth, Carlson, Schmid, & Lucht, 2002), we are a long way from having a systematic screening, identification, and referral process in place for preschool children.

(14) Finding: While the IDEA Part C and Part B programs are a primary resource for identifying young children with suspected disabilities, including behavior challenges, the effectiveness of these systems in identifying young children with challenging behavior is unknown.

An example of supporting research was provided by Kirby et al. (1993) who reported a study using survey/descriptive methods to determine whether composite risk factors for newborns would be predictive of identifying developmental delays at 36 months. They looked at 985 low birth weight, premature infants and found the composite to be non-predictive.

Knowledge Related to Service Utilization

(1) Finding: Young children use mental health services at rates lower than projected need.

Sturm et al. (2000) used data from a variety of national statistical reports and surveys to provide estimates for children's mental health service utilization and cost. Based on three large-scale national surveys, they estimated that 1-2% of preschoolers used any mental health specialty services in a year. In the National Health Interview Study, 4.4% of preschoolers were found to be in need of mental health services, but only 2% of children had received any services. Young children covered by Medicaid had the highest number of mental health outpatient visits per 1000 population, followed by those with no insurance and those with private insurance. Young children with public insurance other than Medicaid had the least number of visits. Inpatient hospitalization for mental health disorders was very low among children 1-5, but again was higher for children covered by Medicaid than for those with other insurance or no insurance. The cost of mental health care for young children was estimated to be divided in the following ways: 65% outpatient visits, 33% inpatient, 9% medication, and 1% other. For young children with private insurance, .7% received some form of psychotropic medication, with stimulants being the most prescribed type of medication.

(2) Finding: Few behavioral health services are being delivered to young children through Medicaid.

During the 1990's the growth of Medicaid managed care has meant that state Medicaid contracts with managed care organizations have become important in determining access and coverage through provisions on capitation, risk management, provider networks, medical necessity criteria and performance standards. Fox (1997) reported that 75% of states had carved out mental health services, 66% had carved out health related special education services, and 45% had carved out early intervention services, creating concerns over the fragmentation of health, mental health and developmental services for children.

Pires, Stroul, & Armstrong (2000) reported that 95% of state managed care reforms include behavioral health services for infants, toddlers and preschool children and their families. However it was found that few behavioral health services were actually being delivered to this population: 56% of states reported that their Medicaid reforms were providing few or no behavioral health services to the early childhood population (Stroul, Pires, and Armstrong, 2001).

Barriers cited in the 1999 impact analysis by the same authors (Pires, Stroul & Armstrong, 2000) include lack of knowledge and expertise among providers concerning interventions for young children, the focus on an "identified patient" that can preclude working with parents especially if they are not Medicaid eligible, strict criteria for medical necessity, the requirement for a diagnosis which is considered by some to be inappropriate for young children, and the requirement for a high level of dysfunction for service authorization.

(3) Finding: Service utilization for young children with challenging behavior is mostly governed by medical professionals.

Lavigne, Arend, Rosenbaum, Binns, Christoffel, Burns, & Smith (1998) investigated the factors associated with mental health service use among children aged 2 through 5 who were seen by primary care physicians. Children who had a Total Problems scale score above the 90th percentile on the Child Behavior Checklist were recruited for the study along with a comparison group matched for age, sex, and race. The most common diagnoses were disruptive disorders including oppositional defiant disorder and attention deficit disorder while emotional disorders or adjustment disorders were less common in this group of young children. The results showed that older children and white children were more likely to receive mental health services (no differences for sex, SES, family size, or intact family). With regard to problems, children with a psychiatric diagnosis, more impaired children, children receiving a pediatric referral for mental health services, and children with larger numbers of behavior problems received more mental health services. In this regard, the presence of a diagnosis doubled the likelihood of receiving services and a pediatric referral increased the likelihood of services more than 2.5 times, underscoring the role of the pediatrician as a gatekeeper in the mental health system.

(4) Finding: There is a high need for Head Start mental health services but resources are not always available to meet the need.

Lopez, Tarullo, Forness and Boyce (2000) report that in 1999, 50% of Head Start programs had a mental health professional available less than 6 hours per week, with a range of more than 20 hours per week (23% of programs) to having a consultant on call as needed (30% of programs). The authors identify needs for on-site vs. on-call mental health consultants, high ratios of mental health professional staff to children served, adequate educational/professional training of mental health staff, and collaborative relationships with relevant community mental health providers.

Piotrowsky, Collins, Knitzer and Robinson (1994) interviewed 78 Head Start directors around the country for mental health usage. 89% reported insufficient mental health resources available. The authors argued for home-based, family supported, integrated services, rather than center based.

Mowder, et al., (1993) provided a content analysis of psychological summary sheets from Head Start providers between 1986 and 1988 (N =510). Of the various patterns of referral, 55% were for “social emotional”. For 66% of the referred children, psychological consultants provided consultation to HS staff, 65% were provided classroom observation, 33% received informal assessment, 24% received parent consultation, 22% were provided with intervention, 17% received formal assessments and 8% received outside consultation. These data supported the social emotional need co-existing with disproportionate referrals for speech/language and the need for psychologist trained to meet the needs of the early childhood population.

(5) Finding: Children in child welfare systems, foster care in particular, utilize a disproportionate share of the mental health services available to young children with challenging behavior.

Given the large numbers of children in foster care and the extent of their needs, foster children consume a large part of the resources devoted to young children with challenging behavior. Halfon, Berkowitz, & Klee (1992) examined Medi-Cal-paid claims to assess the utilization of mental health services by children in the California foster care system. Children in foster care represent 4% of all children in the state yet account for 53% of all psychologist visits, 47% of psychiatrist visits, 43% of inpatient hospitalization, and 27% of inpatient psychiatric hospitalization. Overall, children in foster care have 10 to 20 times the rate of utilization compared to non-foster care children. The authors found that utilization rates and costs were lowest for children under 6 years old. The utilization rates for foster children in this age group were about 20 times greater than the general population of 0 to 6 year olds.

In a similar study of mental health service use by foster care children, Leslie et al. (2000) examined survey, assessment and administrative data on 480 children ages 2–16 years with a mean age of 6.1 years. They found mental health services were used at a rate 10 times the estimated rates for community samples of children. Thirty-one percent of the 1-3 year old children and 19% of the 4-5 year old children had at least one outpatient visit. Mean number of visits increased with age. Latino and Asian/other children had significantly fewer mental health visits than Caucasian or African-American children. Children in kinship care had fewer visits than children in non-relative foster care.

Based on a similar review of incidence rates, Schneiderman, Conners, Fribourg, Gries, & Gonzales (1998) offer a framework for delivering mental health services to children in out-of-home care. The framework consists of a: (1) “prevention-evaluation phase” that would provide mental health screening and assessment to identify problems at the earliest possible time and lessen the negative impacts of placement and separation from family, (2) “treatment phase” that focuses on short-term, intensive interventions for the child and family, and (3) “maintenance phase” to minimize regressions in emotional or behavioral functioning and buffer the impact of delays or failures in the planning process. The authors stress the need for a close working relationship between mental health and child welfare in order to successfully look after the high level of needs represented by children in care.

The US Department of Health and Human Services provided a report of child welfare outcomes for 1999. Using data collected nationally, they examined factors related to service utilization within the child welfare system. While acknowledging the influence of inadequate services, wait lists, family choices, and missing data, they found the following: (1) victims of multiple maltreatments were 112% more likely to receive services compared to children who experienced physical abuse; (2) victims of sexual abuse were 30% less likely to receive services compared to children who experienced physical abuse; (3) prior victims of maltreatment were

78% more likely to receive services than those children with no prior victimization; (4) African-American, American Indian/Alaska Native, Asian/Pacific Islander, and Hispanic children were 45%, 19%, 23%, and 34% more likely, respectively, to receive child welfare services compared to White-non-Hispanic children; (5) Children reported by medical personnel were 17% more likely to receive services than children reported by social and mental health service professionals, and (6) Children older than age 3 were less likely to receive services compared to children ages birth to three.

(6) Finding: IDEA Part C and Part B are serving many young children with disabilities, including some with challenging behaviors.

In 2001, 230,418 children birth through 2 years were being served by Part C, representing 1.99% of the birth through two population. In the same year, 598,922 children were served through Part B, representing 5.04% of all 3- through 5-year old children (Trohanis, 2002).

The National Early Intervention Longitudinal Study (NEILS) is following a nationally representative sample of 3338 infants and toddlers who entered Part C services in 1997-98 (US Department of Education, 2001). When caregivers were asked to rate their children's behavior and functioning it was found that 11% of the children are often aggressive with other children and 50% are sometimes aggressive with other children. Ten percent of caregivers reported that their children had a lot of trouble playing with other children, and 32% reported some trouble playing with other children. Finally, 39% reported that their child was very active and excitable. The report concludes that about a third of the children were reported as having some behavioral difficulties, and 10-40% are described as having behavioral challenges.

As part of the NEILS study, local Part C staff was asked to provide eligibility information for the children in the study (Hebbeler et al., 2001). Based on the descriptors provided by local staff, it was determined that 3.7% of the sample was eligible due to a social/behavioral impairment or delay. The mean age at which these children received their first IFSP was 22.2 months. Eligibility in this category increased with age: for children entering services between 24 and 36 months, 6.2% were eligible due to social/behavioral impairment or delay.

(7) Finding: Family factors, education, race, income, geography, and categorical labeling impact the availability of services and utilization of services for young children with disabilities including those with challenging behavior.

A report from the National Research Council, *Minority Students in Special Education*, (Donovan & Cross, 2002) states that while in 1998-99 Part C was serving 1.63% of all infants and toddlers nationally, this percentage varied widely among the states, from less than 1% in four states to a high of 6.3% in Hawaii. American Indian/Alaskan Native and black children were more likely to receive services than white children while Asian/pacific Islander and Hispanic children were less likely than white children to receive services. This report also cites year 2000 data from the NEILS showing that for all racial/ethnic groups placement in Part C early

intervention services varied with income, with children from lower income families over-represented.

U.S. Department of Education (2001) data for 1999-2000 indicate that in the Part B Preschool Grants Program, Hispanic and Asian/Pacific Islander children are under-represented, white children are over-represented, and to a less extent, black children are over-represented.

Bailey, Skinner, Rodriguez, Gut, and Correa (1999) employed a mixed method design (qualitative and quantitative) to interview 100 Latino mothers and 100 Latino fathers, to determine awareness of and satisfaction with services for their children with disabilities. Parents who were less aware of services had an average of two years less education (8.2 years) than more aware parents (10.2). The recommendation was for greater awareness of the fact that Latino parents may not ask questions and may need proactive assistance to navigate systems of support.

Hanson et al. (2001) conducted a qualitative investigation of family perspectives on factors affecting inclusive educational placements of their children over time (25 children studied). They found that inclusive preschool placements predicted later inclusion over a five-year period. They argued that inclusive placements offer better prevention of the emergence of later problem behavior.

Sontag and Schect (1993) surveyed 536 families in one state by mail to look at access to services as a function of ethnic diversity. They found, predictably, that American Indian families were less likely to receive services. Transportation was rated as the least satisfactory service, with coordination of services in the next most dissatisfaction rated category. They concluded that access to the service system is seriously impaired for American Indian families identified for prevention of problem behavior.

Kochanek and Buka (1998a) studied 133 infants and toddlers receiving Part C services through exemplary programs in three states. They found that older children and those whose mothers had more education were receiving more hours of service. There was a consistent trend in which higher income families received more services than lower income families, however the relationship was not significant. Service intensity was unrelated to race. The authors noted that seven out of the nine programs in the study were serving a disproportionately high number of children living in poverty.

Mallory and Kerns (1998) looked at patterns of access to services as a function of categorical labeling in New Hampshire. Using a descriptive analysis they found that use of categorical labeling for children 3-6 greatly restricts access to needed services. They argued for non-categorical access prior to age 6.

Levanthal, Brooks-Gunn, McCormick, and McCartone (2000) examined patterns of service use in preschool (869 children) who had participated in an early intervention program for low birth weight, premature infants. Their data suggested that patterns of service use addressed

to prevention were identified with reports of effectiveness as opposed to patterns addressed to deficits or response to specific issues.

(8) Finding: Children with disabilities, including those with challenging behavior, may receive low rates of service and often do not receive all recommended services.

Kochanek and Buka (1998a) reported service data on a sample of 133 infants and toddlers being served in exemplary Part C programs in three states. In these programs, children were receiving an average of 1.7 hours of services per week. Older children and those enrolled for a longer period of time were receiving more services. Reporting on the same sample the authors (Kochanek & Buka, 1998b) found that 79% of scheduled services were actually delivered.

Perry, Greer, Goldhammer, and Mackey-Andrews (2001) analyzed IFSPs for 6279 children receiving services through Part C in Indiana to compare the services scheduled to those actually received. They found that on average, 50% of scheduled services were delivered and 24% of the children in the study received no services during the three-month study period. Children receiving no services were more likely to be new to the system: two-thirds of children enrolled less than three months had not received any services, while 90% of children in the program more than four months had received some delivered services. Younger children received fewer scheduled services than older children. On average, children received two hours of services per week, but there was wide variability in service intensity. Only one service category reported in the study, psychological services, might pertain directly to challenging behavior. Only fourteen children had psychological services listed on their IFSPs, and eight had actually received services in this category.

McWilliams et al. (1995) surveyed 539 parents of children birth through five years who were receiving early intervention services. Over-all parents reported high satisfaction with services. However, 21% indicated they needed more help with behavioral control. Thirty-six of the children (7%) in this sample were receiving psychological services.

The U.S. Department of Education (2001) reports NEILS data on service usage categories relevant to children with challenging behavior. In the NEILS sample of children receiving Part C services, 6% were receiving behavior management services, 4% were receiving family counseling/mental health counseling, and 4% were receiving psychological or psychiatric services. Data concerning service providers showed that 2% of the children and families received services from a behavior therapist, 1% received services from a mental health professional/family therapist and 6% received services from a psychologist or psychiatrist.

Conclusions and Recommendations

The purpose of the synthesis is to present a concise picture of the state of empirical knowledge relating to the identification, screening, referral, and entry into service systems for

young children with challenging behaviors. This picture is intended to convey the nature of what is known about service utilization, identify the most conspicuous gaps in current knowledge, and delineate the more prominent needs to be addressed by applied research.

This section is devoted to summary statements, conclusions, and a description of conspicuous gaps in our knowledge that should be most urgently addressed through a program of applied research.

The knowledge base regarding service utilization for young children with challenging behavior yielded several major conclusions:

(1) The prevalence of challenging behavior among young children indicates that this group represents a significant number of children 0-6 years old in the United States. Studies of the rates at which behavior problems occur in young children have used a wide variety of methodologies, instruments and populations and have resulted in a range of prevalence estimates. No studies of prevalence rates for disorders in community samples of children under two years of age were found. Nevertheless, estimates commonly fall within a range of 10% to 20% of the preschool population with challenging behavior.

(2) In recognition of the extent of these challenging behaviors, federal laws and policies mandate screening, identification, and referral services for a significant portion of young children with challenging behavior.

(3) The health care system is a primary gateway for identification, screening, referral, and access to services for young children with challenging behavior. Thus, access to health care and the practices of pediatricians are extremely important elements in determining whether a child receives services. Three federal programs facilitate access to health insurance for low-income young children: Medicaid, the State Children's Health Insurance Program, and the Maternal and Child Health block grant program. Additionally, the American Academy of Pediatrics has developed a policy on Developmental Surveillance and Screening of Infants and Young Children. Virtually all preschool children could be contacted by screening and identification practices contained in the health care system but perhaps about 1/3 are actually screened.

(4) Because large numbers of young children spend time in out-of-home care arrangements, these settings provide important opportunities for identifying children with challenging behavior and forming connections to services. Federally supported early care and education programs (not including IDEA) include Head Start, Early Head Start, Title 1 and the Child Care and Development Block Grant (CCDBG). Only Head Start, Early Head Start and Title 1 mandate screening and mental health services. In addition, 39 states fund prekindergarten programs; 14 of these mandate developmental screening.

(5) Child welfare encompasses protective services, family reunification, foster care, and adoption. While each state has its own child welfare system funded and administered by the state, approximately 45% of the funding for state systems comes from the federal government. There are six major federal programs that provide funding to states for child welfare; all six are administered through the Administration for Children and Families, DHHS. None of these programs contain mandates for mental health screening or services.

(6) The Community Mental Health Services Block Grant Program (CMHSBG), administered through The Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, awards grants to states for services to adults and children with serious mental disorders. The grants are designed to support existing public services and the development of systems of community-based care. However, there is little regulation on how the funds are to be spent by states. Because of the competing demands on these funds and the requirement that they be used for children with severe emotional disturbance, very little of the money is spent on services for children under six years and there is no mandate or set-aside funds for prevention.

(7) The Individuals with Disabilities Education Act (IDEA) Part B provides funding for educational services to children 3-5 years of age with disabilities as well as children 6-21, through public education agencies. The Part C Program provides funding for early intervention services for children 0-2 years with disabilities. In addition, Part C mandates the creation of coordinated, comprehensive multi-disciplinary programs that include outreach, early identification, screening, assessment, referral, and case management. While the law does mandate critical components, states also have broad latitude in how they administer and implement the mandates and in determining outcomes and indicators. Each state must designate a lead agency and these vary from state to state but include health, education, social services, developmental services, economic security, rehabilitation services, mental retardation, and public health agencies.

(8) Current systems are inadequate to serve the needs of young children with challenging behavior.

(9) In health systems, screening and identification services are mandated for all eligible young children and must include a mental health assessment. However, fewer than 1/3 of the eligible children receive a full EPSDT screen and even fewer receive a screen that includes behavioral health.

Medicaid mandates further testing or assessment for those young children screened positive for challenging behavior. However, few behavioral health services were actually being delivered to this population (e.g., 56% of states reported that their Medicaid reforms were providing few or no behavioral health services to the early childhood population).

Pediatricians correctly identify only a small portion of young children with challenging behavior (estimates range from 17% to 40%).

Significant barriers to identification and referral of young children with challenging behavior exist in the medical profession. Training and the use of special screening tools seems to improve the pediatricians ability to accurately screen for problems among young children with challenging behavior.

“Model” programs exist that take a more proactive and evidence-based approach to screening and referral for preschool children with challenging behavior

(10) While IDEA Part C and Part B programs are a primary resource for identifying young children with suspected disabilities, including behavior challenges, the effectiveness of these systems in identifying young child with challenging behavior is unknown.

(11) Children with challenging behavior can be identified among those in the preschool environments, however biases may exist in identification and referral systems for young children with challenging behavior.

(12) Mental Health Systems for very young children are almost non-existent.

(13) Children placed in child welfare services often have a complex array of challenging behavior and consume a disproportionate share of resources devoted to the problems of young children.

(14) With respect to service utilization, young children use mental health services at rates lower than the projected need. Studies indicate that service utilization for young children with challenging behavior is mostly governed by medical professionals. Family factors, education, race, and income impact the availability of services and utilization of services for young children with challenging behavior in early intervention systems. There is a high need for mental health services within Head Start but resources are not always available to meet the need. Family-centered practices and a broader approach to young children with challenging behavior is needed in child care systems. Children in child welfare systems, foster care in particular, utilize a disproportionate share of the mental health services available to young children with challenging behavior.

(15) There is little evidence that services are accessed across and between systems in a coordinated manner that expedites comprehensive care for young children and families affected by challenging behavior.

These conclusions are based on little data, so it is important to recognize them as tentative. As shown in this synthesis, there is insufficient evidence to draw very definite conclusions. The gaps in knowledge are glaring and will require a concerted research effort over

many years to fill in the blanks so more reasoned and effective policies and procedures can be enacted and implemented on a national basis. This is, however, an important item on the national agenda. Many of the more severe forms of health, mental health, educational, social service, and child caring problems seen later in life have their roots firmly planted in the preschool developmental years. Future generations stand to benefit greatly from a more reasoned and integrated effort to detect and treat the earliest problems associated with young children with challenging behavior.

The following **recommendations** are based on the information (and lack of information) reviewed in this document:

(1) Screening and identification of young children with challenging behavior needs to be based on a growing body of literature that relates problems of early childhood development with later behavioral health problems (e.g., Institute of Medicine, 1994, *Reducing risks for mental disorders*). In this way, screening can more effectively and efficiently identify those problems most predictive of later, more severe challenging behaviors.

* There is a need for longitudinal research, retrospective and prospective, that carefully charts the development of challenging behaviors in the preschool years. For example, retrospective research can document the earlier beginnings of challenging behavior among children who currently are experiencing more advanced problems. The ways in which the challenging behavior emerged, the kinds of family supports that seem to impact the emergence of challenging behavior, the kinds of services that were attempted, and so on could help to provide a picture of the pathways to challenging behavior in the early years. Prospective research can further investigate these apparent pathways to test their validity.

* Research is needed to discover effective ways to make contact with families of children who have challenging behavior so they will participate in screening and identification protocols and seek support and services. Public information campaigns, information provided as part of community-based immunization programs, public health partnerships, and other forms of outreach and enrollment can be used to engage families. Such efforts can be systematically applied, compared, and evaluated for their effectiveness in reaching the families identified in the prevalence surveys.

* Studies are needed to develop and evaluate screening systems that are based on longitudinal research and practical for use at a community level and in primary health care settings. For example, screening systems need to be developed to fit within the limitations of time and opportunity in the interactions between a pediatrician and a family with young children yet are sensitive in identifying young children with challenging behaviors. Research is needed to evaluate the training that needs to be provided to pediatricians to carry out the screening protocols. Additional between-group research is needed to evaluate the efficacy and effectiveness of those screening protocols with respect to important outcomes such as improved behavioral health and family supports.

* Research is needed to further expand the knowledge bases of innovative programs such as the Hawaii Healthy Start Program with regard to screening and identification of newborns who are at risk of developing later challenging behavior. The success of such innovative, community-wide programs may provide promising direction for prevention efforts and for national policy makers.

(2) Referral systems need to be established to connect the families of young children with challenging behavior with appropriate supports and services.

* Research is needed to develop referral systems that are attuned to the needs of families and the variety of services available in order to match needs with appropriate services. This is a critical step in the process of ameliorating challenging behavior at an early stage. The “hand-off” from the screening-identification systems needs to be seamless and engaging for families so they will actually contact the help that is needed.

* Research is needed to find the most effective ways to provide referral information to families in order to assure their follow-through on referral recommendations and to help guide the development of a coordinated system of effective care.

(3) Nationally-available service systems need to be established to serve the needs of young children with challenging behavior.

* Given the prevalence of challenging behavior among preschool children, research is needed to help establish supports and services that are available to children and families nationally. These evidence-based programs would help to fulfill the mandates already established in federal laws and policies at a national level.

* Research is needed to establish systems for identifying and replicating evidence-based programs so that effective services can be made available. For example, criteria need to be established to define a successful evidence-based program. Such programs then can be replicated on a broader scale where the more general applicability and success of the program can be further developed and tested *en route* to national implementation to benefit young children with challenging behavior.

* Research is needed to establish and evaluate staff selection, training, and coaching systems necessary to support the implementation of effective programs nationally.

* Research is needed to evaluate the longer-term impacts of various supports and services delivered to preschool children with challenging behavior.

* Research is needed to develop more comprehensive (less categorical and more ecological) supports and services that encompass a variety of child and family factors for young children with challenging behavior.

(4) Research is needed to establish effective policies with regard to federal and state funding and regulation of systems for screening, identification, referral, and supports and services for children with challenging behavior.

* Research is needed to compare various policies and regulations across several states with respect to their usefulness in identifying and providing supports and services to children with challenging behavior. For example, some states use managed care approaches that limit services to a single person as a defined patient while other states allow the family to be considered as the defined patient. Some states do not pay for attendance at collaboration meetings while others encourage such attendance to plan wraparound services for young children. These natural variations and others can be evaluated through careful research to discover which approaches (or components of approaches) are most useful for helping young children with challenging behavior. The apparently successful approaches then can be implemented in a systematic way that allows for a more carefully researched set of outcomes.

* Research is needed to assess the degree of implementation of current policies designed to help young children with challenging behavior. Federal and state laws and regulations currently in place can be assessed to identify the ways in which extent to which they actually have been implemented at the levels of application. This research would help legislators, policy makers, and regulators in their efforts to craft policies that are most helpful to young children with challenging behavior.

* Research is needed to obtain information from families with children with challenging behavior concerning their experiences in seeking help in order to develop screening, referral, and access processes that meet the needs and preferences of families, including families from different ethnic and cultural backgrounds.

The recommendations and research themes outlined here are quite broad and reflect the need for basic information about the policies, processes, and procedures involved in successful approaches to the problems of young children with challenging behavior. As the research findings become known, a more targeted approach to research will be possible. However, the investment in research and systems development is critical in order to find solutions to this significant behavioral health problem.

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Table 1: Pathways to Screening, Identification, and Service Utilization

Funding Stream	Program	Agency	Services	Eligibility
Healthcare	Medicaid	Centers for Medicare & Medicaid Services (CMS), DHHS	Healthcare, including behavioral healthcare. EPSDT screening and services. Outreach & case finding. State waivers allow coverage of home & community-based services. (CMS, 2002a & b)	Children <6 yr in families below 133% FPL. SSI recipients. Optional: infants < 1 yr in families below 185% FPL. (CMS, 2002c)
	State Children’s Health Insurance Program	Centers for Medicare & Medicaid Services, DHHS	Healthcare, through expanded Medicaid eligibility or separate health insurance program. Outreach, enrollment services & facilitative services. (CMS, 2002d)	Children in families up to 200% FPL or up to 50% above state Medicaid eligibility levels that are >150% FPL. (CMS, 2002d)
	Maternal and Child Health Block Grant Program	Maternal and Child Health Bureau (MCHB), DHHS	Improved access to quality health care for pregnant women and children through infrastructure building services, population-based services and enabling services. (MCHB, n.d.)	Low income children. Children with special healthcare needs. States determine specific eligibility criteria. (MCHB, n.d.)
Early Care and Education	Early Head Start	Head Start Bureau, Administration for Children & Families (ACF), DHHS	Individualized child development & parent education services. Center-based and family child care home-based care. Developmental screenings & mental health services. Home visiting, case management & peer support for parents. (ACF, 2002c & 2002e)	Infants and toddlers up to the third birthday in families up to 100% FPL. At least 10% of slots in each program must be available to children with disabilities. Low income pregnant women. (ACF, 2002d & 2002e).
	Head Start	Head Start Bureau, Administration for Children & Families, DHHS	Center-based early care and learning program. Parent involvement. Developmental screenings & mental health services. (ACF, 2002e)	Children 3-5 years in families up to 100% FPL. At least 10% of slots in each program must be available to children with disabilities. (ACF, 2002d & 2002e).

	Child Care and Development Fund	Child Care Bureau, Administration for Children & Families, DHHS	Subsidies for care in centers and family child care homes meeting licensing requirements, and by relative caregivers. No federal requirements for developmental screenings or other services. (ACF, 1998)	Children in families at or below 85% of state's median income. Parents must be working, transitioning off public assistance or at risk of requiring public assistance. Priority given to children in very low-income families, children with special needs and children in need of protective services. (ACF, 1998).
	Title I Preschool Programs	U.S. Dept. of Education (USDOE)	School-based preschool programs, which must meet Head Start performance standards. Funds may also be used for parent involvement and education and may be combined with other preschool funding. (USDOE, 1996; USGAO, 2000)	Children from low income families at risk of failing to meet state's student performance standards. (USDOE, 1996; USGAO, 2000)
	State Prekindergarten Programs	State funded and administered	School and center-based preschool programs. (Mitchell, 2001; Scrivner & Wolfe, 2002)	Low income preschool age children. Eligibility criteria differ among states. (Mitchell, 2001; Scrivner & Wolfe, 2002)
Child Welfare	Child Welfare Services Program; Promoting Safe & Stable Families Act; Foster Care & Adoption Assistance Act; Child Abuse Prevention & Treatment Act; Adoption & Safe Families Act	Children's Bureau, Administration for Children and Families (ACF), DHHS	Funds can be used to support various aspects of state child welfare systems and services including intervention with families at-risk or in crisis, and mental health treatment and intervention for children. (ACF, 2002a; ACF, 2002b)	Children in child welfare system due to abuse/neglect or at-risk for abuse/neglect. (ACF, 2002a; ACF, 2002b)
Mental Health	Community Mental Health Services Block Grant Program	Center for Mental Health Services, SAMHSA, DHHS	Grants to states to support existing public mental health services. Development of systems of community-based mental health care. (National Mental Health Information Center, 2003)	Children with serious emotional disturbance. (Center for Substance Abuse Treatment, 1998)

Early Intervention	IDEA Part C: Infants & Toddlers with Disabilities Program	Office of Special Education Programs, Office of Special Education and Rehabilitation Services (OSERS), USDOE	State systems of outreach, identification, screening, assessment, referral, case management and services including family training and counseling, psychological services, and service coordination. (OSERS, 1997)	Children birth to third birthday with delays in one or more developmental areas, including social & emotional; or with physical or medical conditions likely to cause a developmental delay. States determine specific eligibility criteria States may elect to serve children at risk for developmental delay. (OSERS, 1997)
	IDEA Part B: Preschool Grants for Children with Disabilities Program	Office of Special Education Programs, Office of Special Education and Rehabilitation Services USDOE	Outreach, identification and evaluation through Child Find, including coordination with Part C activities. Transition from Part C to Part B services. Special education and related services including psychological services, parent counseling and training. (OSERS, 1997)	Children from 3-5 years with disabilities. States may also elect to serve 2 year old children. (OSERS, 1997)

Notes for Table 1: The information contained in Table 1 is based on our review of the literature and government documents (see the text). These funding streams, programs, agencies, services, and eligibility requirements are changed frequently. The reader should seek current information for any area of interest. “EPSDT” refers to Early and Periodic Screening, Diagnosis, and Treatment. “FPL” refers to the Federal Poverty Level, an income level specified by the federal government. “SSI” means Supplemental Security Income. “IDEA” refers to the Individuals with Disabilities Education Act. The “USDOE” is the US Department of Education. “SAMHSA” is the Substance Abuse and Mental Health Services Administration within “DHHS,” the Department of Health and Human Services. See the text for references to source documents.