

REPORT

Promoting Social-emotional Wellbeing in Early Intervention Services

A Fifty-state View

Janice L. Cooper | Jessica Vick

September 2009



National Center for Children in Poverty
Mailman School of Public Health
Columbia University

The National Center for Children in Poverty (NCCP) is the nation's leading public policy center dedicated to promoting the economic security, health, and well-being of America's low-income families and children. Using research to inform policy and practice, NCCP seeks to advance family-oriented solutions and the strategic use of public resources at the state and national levels to ensure positive outcomes for the next generation. Founded in 1989 as a division of the Mailman School of Public Health at Columbia University, NCCP is a nonpartisan, public interest research organization.

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Janice L. Cooper, Jessica Vick

AUTHORS

Janice L. Cooper, PhD, is interim director at NCCP and assistant clinical professor, Health Policy and Management at Columbia University Mailman School of Public Health. Dr. Cooper directed NCCP's early childhood work from February to August 2009.

Jessica Vick, PhD, was a senior research analyst at NCCP until 2009.

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- EXECUTIVE SUMMARY 4
- INTRODUCTION..... 7
- PART 1: Overview and Purposes of Part C 8
 - Establishment of Part C
 - Changes to Part C from 1986 to the Present with Implications for this Study
- PART 2: Study Rationale and Methodology 10
 - Survey Rationale
 - Methods
 - Screening, Referral and Evaluation
 - Services to Infants and Toddlers
 - Attending to the Needs of the Most Vulnerable
 - Leadership and Special Initiatives
- PART 3: Study Findings 14
 - Section 1: Part C Screening, Referral and Evaluation Mechanisms
 - Section 2: Services to Infants and Toddlers Eligible for Part C
 - Section 3: Services and Supports to At-risk, Non-eligible Infants and Toddlers
 - Section 4: Leadership and Special Initiatives
- PART 4: Key Findings, Policy Implications and Recommendations 22
 - Summary of Findings
 - Policy Implications
 - Recommendations
- References 26
- Appendix A1: Survey of State Part C Agencies (paper copy) 28
- Appendix A2: Survey of State Part C Agencies (online copy)..... 32
- Appendix B: State Part C Programs by Lead Agency, Eligibility and At Risk Status..... 37

EXECUTIVE SUMMARY

Introduction

In 2007 approximately 322,000 young children received services through the Individuals with Disabilities Act (IDEA) Part C, the Early Intervention Program for Infant and Toddlers with Disabilities. Yet research shows that only a fraction of children eligible for the program received services. Against the backdrop of this gap between need for services and service use, special concerns for young children with or at risk for social-emotional developmental delays stand in relief. Even fewer of these children received services to address their social-emotional developmental needs through Part C. In part, this state of affairs reflects the significant flexibility states have in the eligibility criteria used to identify children who will receive services under Part C. However, this flexibility results in significant differences in the number of children identified in specific states.¹ Eligibility criteria are categorized into three groups: *restricted*, which includes in the determination neither clinical input nor children at-risk for developmental delay; *narrow*, which does include a clinical option but not at risk children; and *liberal*, which can include both the clinical option and at-risk children.

Purpose

The aim of the study reported in this brief was to determine how states leveraged different policy choices to support integration of social-emotional developmental strategies into early intervention services. Forty-eight states' Part C coordinators participated in the study. They reported on their states' efforts to support screening, referral and evaluation; strategies that are part of the array of early intervention service continuum covered by the Part C program; services and supports to children who are at risk and who are not eligible for Part C; and coordination and leadership.

Key Findings

In order to address the mismatch between service needs and availability for children with social-emotional developmental needs effective collaboration between Part C and other federal programs and initiatives is needed. States' policy choices yield mixed results regarding their potential to support better integration of strategies designed to address social-emotional developmental delays into early intervention services. A number of strategies are being used by states to foster better integration. One of the study's most promising findings is that most states (70%) recommend the use of validated screening tools to detect social-emotional developmental delays. The Ages and Stages Questionnaire (ASQ) and the Ages and Stages Questionnaire: Social-Emotional (ASQ:SE) were the most frequently mentioned recommended tools. In addition, nearly 90% of states are involved in efforts to promote early identification by primary care physicians. Nearly all states (96%) have state-wide data to measure child performance regarding improved social-emotional skills. Some states have also developed a solid platform for measuring and monitoring progress.

The study reveals several policy challenges which impede states' abilities to support young children who have, or are at risk of developing, social-emotional developmental delays. In particular, fewer than two-fifths of states require that a professional with expertise in social-emotional development sit on the multi-disciplinary evaluation team required to determine eligibility for early intervention services. Among services available through Part C, only half of states support infant-toddler relationship-based training (a core component of a range of research-informed services) and only one-third of states include respite care. States were most likely to pay for group or individual parenting training (73%). While research indicates that group training for parents is not effective for this age group, the survey did not ask respondents to distinguish between group and individual parent training.

No questions related to the quality of the parenting interventions were asked. Finally, while not required by legislation, only 17 states had written agreements in place to guide referral and services for young children. This is significant given both recent federal mandates that require coordination between Part C and child welfare, and data that show poor access to mental health services for young children in child welfare.²

Recommendations

Screening and Assessments

- ◆ For clinicians and others who make eligibility determinations and provide services at the child and family level, states should support the use of, and the federal government should encourage and fiscally incentivize where possible, valid instruments for screening and assessment of infants and toddlers at risk for social-emotional developmental delay.
- ◆ When screening infants and toddlers for developmental delay, valid, multi-domain screening tools that are also designed to identify problems in the social-emotional domain should be used, such as the Infant-Toddler Development Assessment (IDA). Alternatively, a general screening tool should be supplemented by using a screening tool designed specifically for the social-emotional domain, such as the ASQ:SE.
- ◆ States and the federal government should support – through funding if necessary – high quality training and technical assistance to ensure implementation fidelity of the existing valid screening and assessment tools for clinicians and others involved in eligibility determinations and who provide treatment and supports at the child and family level.

Empirically Supported and Family Responsive Services

- ◆ States, the federal government, and tribal jurisdictions should, through funding and by ensuring them as part of benefit sets, support the availability of empirically supported and family responsive services to meet the needs of young children with social-emotional developmental delays or at risk for such delays. Minimally, all states should be required to provide, where

clinicians indicate the need, access to a range of evidence-based interventions and support for young children. In particular, relationship-focused dyadic infant and toddler interventions should be available in the service array of state Part C programs.

- ◆ States, the federal government, and tribal jurisdictions should undertake training and technical assistance to support the widespread adoption of evidence-based or empirically supported interventions to address the social-emotional developmental needs of young children eligible for Part C programs and for clinicians to whom young children at risk for developmental delays are referred.

Outcomes and Accountability

- ◆ The United States Education Department, Office of Special Education Programs (OSEP) should publicly and annually report on indicators for social-emotional wellbeing for children with social-emotional developmental delays who receive services through the Part C program.
- ◆ OSEP should develop targets for increasing the availability of services to address the social-emotional developmental needs of young children served in the Part C program.
- ◆ OSEP should report on indicators for social-emotional wellbeing for children who receive services through the Part C program by race and ethnicity, in light of the evidence of the disparities in access to needed services previously documented.³

Promotion of Wellbeing, Prevention of Ill Health and Early Identification

- ◆ States, OSEP, and tribal jurisdictions should report on those children deemed at risk of a social-emotional developmental delay who do not meet the eligibility criteria for Part C.
- ◆ OSEP, working in concert with states, should develop guidelines for how and where to refer children who are at risk and do not meet eligibility criteria.
- ◆ States, tribal jurisdictions, and OSEP should track and report referrals for children deemed at risk for social-emotional developmental delay who do not meet the eligibility criteria for Part C.

Support for Service Enhancement and Service Coordination Especially for the Most Vulnerable Children

- ◆ Policies and financial resources at the federal, state, and tribal jurisdictional level should be better coordinated and aligned to support cross-agency planning, implementation, and evaluation of resources and supports to adequately address the needs of infants and toddlers and their families. The federal government and states should place a moratorium on the creation of additional coordinating bodies and improve and work through existing efforts to meet the need for services integration and coordination.
- ◆ Federal policy and resource allocation should be designed to ensure that all young children receive the resources and supports that they need.

The Need for More Information

- ◆ The federal government should underwrite a study to identify all potentially available federal, state, public, and private resources to support screening, evaluation and service delivery for young children with or at risk for social-emotional developmental delay.
- ◆ The federal government, in partnership with private groups, should support research and dissemination of valid and reliable instruments for screening and assessment and ensure that these are culturally competent and appropriate to infants and toddlers.

INTRODUCTION

Young children with disabilities and sometimes those at risk for disabilities are entitled to early intervention services and supports as early as possible under the Individual with Disabilities Educational Act (IDEA), Infants and Toddlers with Disabilities.⁴ For children up to age 3 years old, these services are governed by Part C of the IDEA legislation. In 2007, an estimated 322,000 young children received early intervention services funded through Part C.⁵ Over half of these children were two years old, approximately one-third were between 12 and 24 months and 14 percent were less than one year old.

Increasingly, researchers and policymakers have paid attention to the social-emotional wellbeing of young children. Infant and toddler social-emotional wellbeing is linked to social competence, and the ability to maintain healthy relationships and self-regulation. All of these are characteristics associated with positive outcomes related to children's health, development and academic performance.⁶ Young children who exhibit signs of poor emotional regulation, social interactions and impaired relationships need early intervention services and supports to: (1) prevent, reduce or ameliorate conditions; (2) optimize their parents' ability to support, manage and address their conditions; and, (3) to maximize opportunities to benefit from addressing problems before or at their onset.⁷ However, fewer than three percent of children who receive Part C services have received psychological services, and fewer than 20 percent have received family counseling, training or home visits, according to the last available data.⁸ In addition, among the 3 to 4 year olds who receive special educational services, the proportion who are identified as having social, emotional, and behavioral problems remains small (less than 3%). Yet, 25 percent of parents of young children who received early intervention services reported that their children were overanxious, showed signs of problems with social interaction, and were hyperactive or depressed.⁹ These data suggest that efforts are needed to enhance early identification of children

at risk for social-emotional developmental delay or with social-emotional developmental problems and to provide services to those children with behavioral health needs that may be a secondary condition.¹⁰

Project Overview

This report describes findings from a national survey of state Early Intervention coordinators (known as Part C coordinators) on the availability of an effective policy framework to support the social-emotional wellbeing of young children within the context of the nation's early intervention program. NCCP undertook a survey of state Part C coordinators to determine whether states were maximizing current policies, including fiscal policies, to provide effective child development and prevention services to young children, especially those at risk of social-emotional delays. A separate report on four case studies will follow the survey results presented here.

The report is organized into four parts.

- ◆ Part 1 provides an overview of IDEA's Part C.
- ◆ Part 2 explains the study rationale and methodology.
- ◆ Part 3 lays out the findings of the study.
- ◆ Part 4 presents a summary of the key findings, the implication for public policy, and recommendations.

PART 1

Overview and Purposes of Part C

Establishment of Part C

Congress' 1986 enactment of P.L. 99-457 established Part H (now Part C) of the federal education disability law, which became the "Individuals with Disabilities Education Act" (IDEA). The primary purpose of this program was to provide financial assistance to states to develop and implement a "statewide, comprehensive, coordinated, multidisciplinary, interagency program of early intervention services for infants and toddlers with disabilities." Although states are not required to participate in the Part C Program, as of June 2009, all states continue to participate. To receive a Part C grant, the governor must designate a lead agency to administer the program on behalf of the state. The state, through the designated lead agency, is required to ensure that all requirements of Part C are met, and must submit state policies and procedures that are consistent with federal regulations.

Federal Part C requirements include:

- ◆ Child Find (public awareness activities to locate, identify, and refer children with disabilities);
- ◆ a rigorous eligibility definition;
- ◆ evaluation and assessment;
- ◆ Individualized Family Service Plans (IFSPs);
- ◆ appropriate early intervention services;
- ◆ natural environment (settings that are typical for the child's peers who have no disabilities);
- ◆ personnel standards;
- ◆ procedural safeguards;
- ◆ a comprehensive system of personnel development; and
- ◆ a state interagency coordinating council.

Individualized Family Services Plan (IFSP)

A written plan developed for each child and family that includes:

- ◆ developmental status of the child;
- ◆ with parent consent, concerns, priorities and resources;
- ◆ outcomes for child and family;
- ◆ services that must be made available for the child and family; and
- ◆ a requirement that the plan be reviewed at least every six months and revised annually.

States participating in Part C are required to include in their eligibility definition for children, birth to 3, who need early intervention services because they have:

- ◆ developmental delays, as measured by appropriate diagnostic instruments and procedures in one or more of the areas of cognitive development, physical development, communication development, social or emotional development, and adaptive development; or
- ◆ a diagnosed physical or mental condition that has a high probability of resulting in developmental delay.

Each state determines the criteria to be used for defining developmental delay. Some states use percentage delay, others use standard deviation and others a combination of the two. Most recent data available indicate that:

- ◆ 19 states use percentage of delay only;
- ◆ six states use a standard deviation only;
- ◆ 23 states use a combination of percentage delay and standard deviation;
- ◆ seven states do not specify a criteria; and
- ◆ one state specifies criteria in number of months delay.¹¹

A state may, but is not required to, include children who are at risk of having substantial developmental delays if services are not provided. There are currently only seven states and one territory that include children who are at risk of developmental delays.¹² These include California, Guam, Hawaii, Indiana, Massachusetts, New Hampshire, New Mexico, North Carolina and West Virginia.

Changes to Part C from 1986 to the Present with Implications for this Study

Congress has reauthorized the Part C program several times since 1986, making changes, some significant, each time. In 1997, a new policy statement was added reflecting the emphasis, “to encourage states to expand opportunities for children less than 3 years of age who would be at risk of having substantial developmental delay if they do not receive early intervention services.”

The 1997 reauthorization added language to permit states that do not serve at-risk infants and toddlers to strengthen the statewide system to improve collaborative efforts. This allowed states additional resources to expand linkages with appropriate public or private community-based organizations, services, and personnel.

The reauthorization in 2004 made additional changes to Part C designed to ensure that all children, especially those at risk for developmental delay or disability, have access to the Part C system. These changes did not require an expansion of the state’s eligibility criteria but emphasized access for children who may have not traditionally been referred or evaluated. The Congressional Report accompanying the reauthorization legislation clearly stated, “the Conferees intend that the public awareness program include a broad range of referral sources such as homeless family shelters, clinics and other health service related offices, public schools, and officials and staff in the child welfare system.”

These IDEA 2004 changes included:

- ◆ the addition of new language that required the state interagency coordinating council to include members from the state Medicaid agency, the Office of the Coordinator of Education of Homeless Children and Youth, the State child

welfare agency responsible for foster care, and the state agency responsible for children’s mental health;

- ◆ the addition of language, consistent with new Child Abuse Prevention and Treatment Act (CAPTA) enacted in 2003, requiring states to include in their federal Part C application and assurances, a description of policies and procedures that require the referral for early intervention services of children under the age of 3 who:
 - are involved in a substantiated case of child abuse or neglect; or
 - are identified as affected by illegal substance abuse, or withdrawal symptoms resulting from prenatal drug exposure.

The Congressional Report accompanying the IDEA reauthorization legislation provides additional language emphasizing Congressional intent as follows: “The Conferees intend that **every child** [described above] **will be screened** by a Part C provider or designated primary referral source to determine whether a referral for an evaluation for early intervention services under Part C is warranted. **If the screening indicates the need for a referral, the Conferees expect a referral to be made. However, the Conferees do not intend this provision to require every child ... to receive an evaluation or early intervention services under Part C.**”

The reauthorization of CAPTA in June of 2003 made these changes necessary. CAPTA requires that states have provisions and procedures for the referral of children under the age of three with substantiated cases of child abuse or neglect to early intervention services funded by Part C.

A proposed set of revisions to the Part C regulations that would implement changes made by IDEA 2004 was published for comment in May 2007 but no final regulations have been promulgated to date.

PART 2

Study Rationale and Methodology

Survey Rationale

Research shows that early intervention to support healthy social-emotional development for young children at risk of delays because of poverty, familial, biological or environmental risks is vital for promoting positive child health, development and early school outcomes.¹³ However, there is evidence that current identification efforts and service delivery and support systems do not adequately meet the needs of young children with social, emotional, and behavioral problems. There is inadequate screening for social, behavioral, and emotional problems in young children.¹⁴ Furthermore, those children who are identified often lack access to early intervention services.¹⁵

Although many states recognize the barriers to identifying and providing services for young children with behavioral, social, and emotional difficulties, crafting a coherent policy response across funding and service agencies remains challenging. The current federal policy and fiscal structure does not make it easy to provide early intervention to young children who show signs of social-emotional delays but whose conditions do not reach a diagnosable level. Part C of IDEA has the option of including infants and toddlers *at risk of* delays in its eligibility criteria, but only a small number of states have used this provision.¹⁶

The purpose of the survey of the *50-state Survey of Part C Agencies Regarding Screening and Services* (See Appendix A1-A2) was to examine, drawing on data from key informants at the state level, how states implement Part C to identify and meet the needs of children with social-emotional

developmental delays. Specifically, NCCP asked states about their Part C screening, referral mechanisms; services for infants and toddlers eligible for Part C; services and supports for children who are at risk, but not eligible; and any leadership and special initiatives around integrated early intervention services. This and other data can inform efforts to promote policy change strategies at the state, regional and national levels and support a more coherent and effective policy framework that ultimately better serves the unmet needs of children at risk for and with social-emotional developmental delay.

Methods

NCCP, in conjunction with a panel of experts,* developed a set of questions that probed for both agency specific and cross-system state capacity to identify, track, serve, and monitor outcomes for young children in need of health and developmental services linked to social, emotional and behavioral conditions. Part C coordinators were asked the extent to which their states do each of the following:

- ◆ provide screening and diagnostic assessment to identify social-emotional problems and have mechanisms in place to track referrals;
- ◆ monitor young children who have identified risk factors but are ineligible for individual services;
- ◆ provide access to preventive, early intervention, and treatment services for infants and toddlers experiencing or at risk of social-emotional problems, and their families; and
- ◆ participate in community efforts to build infrastructure to support an array of early intervention services and supports and to track what happens to children identified early.

* Dr. Edward Schor and Melinda Abrams (Commonwealth Fund), Dr. Mary Beth Bruder (University of Connecticut), A. J. Pappanikou (Center for Excellence in Development Disabilities Education, Research, and Service), Sheryl Dicker, Esq. (Permanent Judicial Commission on Justice for Children), Dr. Mimi Graham (Florida State University Center for Prevention and Early Intervention Policy), Maureen Greer (Emerald Consulting), Erica Lurie-Hurvitz, Esq. (Zero to Three), Neva Kaye (National Academy for State Health Policy), and Dedra Jones Markovich (The Ounce of Prevention Fund).

The original survey instrument was developed between September and December, 2006 (see Appendix A1) and consisted of 18 questions. The survey was sent to the field January 26, 2007. As a result of the first, second, and third rounds of contact, 22 states responded to the NCCP survey.

To increase the response rate, NCCP developed a shorter (12 question) instrument (see Appendix A2), through Survey Monkey, which Part C coordinators could complete over the Internet. An invitation to complete the survey was sent via email to all state Part C coordinators. Those who had already completed the longer version of the survey were sent their initial responses and were asked to update any information that had changed. All of the e-mail requests were followed up by phone calls and e-mail reminders. In total, NCCP received new responses from 26 states, for a total of 48 out of 50 (96%) states who responded to the survey. One state declined to participate and no response was received from the other state.

The survey is comprised of four sections:

- ◆ Section 1: Part C Screening, Referral and Evaluation Mechanisms;
- ◆ Section 2: Services to Infants and Toddlers Eligible for Part C;
- ◆ Section 3: Services and Supports to At-risk but Not Eligible Infants and Toddlers; and
- ◆ Section 4: Leadership and Special Initiatives.

The process for developing the lines of inquiry for this study was informed by extant research on child development, services research and policy documents. Below we outline the research basis for the lines of inquiry pursued through this study.

Screening, Referral and Evaluation

Screening and assessment to guide program planning, accountability, and service quality is pervasive.¹⁷ The Part C program is no different. As the practice of using assessments has increased, calls to ensure that they are administered in a systematic manner, which lacks intrusion where possible and demonstrates fidelity to ethical guidelines, have grown.¹⁸ Screenings represent a component of these efforts. Study investigators sought to identify

whether states' screenings for early intervention services included indicators in the social-emotional domain, whether screening tools were standardized, and what type of expertise was available to assess the need for developmental services in that domain. They also were interested in what referral mechanisms existed and whether referrals were tracked.

Mounting evidence suggests that young children who may be in need of developmental services are not being identified and served at an early age. Some are not being identified at all. A recent study shows that an estimated 13 percent of children are eligible for Part C services but only two percent receive them.¹⁹

Accessing services and supports early is critical since research demonstrates the effectiveness of early intervention.²⁰ In addition, research shows that access to pediatric services among young children is nearly universal, but that quality of care among clinicians that serve young children often misses the mark. While nearly all young children have access to pediatric care (98%), fewer than 40% to 53% received guideline level care for preventive and medical care.²¹ Therefore primary care providers, particularly pediatricians, have been targeted for special attention, both as a linchpin for quality early detection and for referrals to specialty early intervention and related services.²²

Studies show that primary care providers are not consistent users of standardized screening tools that are designed to accurately detect problems. Over 70 percent of pediatricians report they regularly rely on non-standardized methods to detect developmental delays in children birth to 3.²³ Only 23 percent report that they consistently used a standardized tools despite the effectiveness of such tools over other methods.²⁴ Other research suggests that primary care providers do not consider all the information they need before deciding to refer children, and that when they refer, they do not always make reliable referrals. While the evidence and philosophical framework takes into account the importance of parental reports in assessments, one study reports no difference in actions or referrals based on parental concerns.²⁵ In other instances, many physicians depend on a medical diagnosis versus indicators of developmental delay to make a referral, thereby leading to potential under-referrals.²⁶

Combined with states' efforts to recommend standardized tools, states are also advancing strategies to support primary care providers as they effectively screen and refer.²⁷ One state's efforts to promote screening in pediatric offices through training, support for workflow management in the clinical setting and consultation on the use of a standardized, validated screening tool resulted in increases in screening for young children from 15% of the time to over 70%.²⁸ Among the queries made of State Part C coordinators was to report on their states' efforts to promote screening among primary care providers.

Services to Infants and Toddlers

Access to quality services for young children with social-emotional developmental delays or at risk for related developmental problems encompasses not only identification and referral, but also actual receipt of care. Research demonstrates the effectiveness of particular types of interventions.²⁹ Key components of effective strategies for early intervention designed to address social-emotional conditions include preventive measures; relationship-focused, family centered interventions; and treatment strategies that address psychopathology.³⁰ These strategies engage the child within the context of the family, enhance parents' knowledge about parenting and parenting skills, target interactions between young children and their parents or primary caregivers, provide specialized supports to caregivers as needed, include models that reinforce the child and family's natural environments, and provide opportunities and support for parents to offer supportive and nurturing care.³¹ Among the service types that investigators asked states about for this study were strategies that incorporated these core principles, including relationship-based dyadic or family therapy and respite care.

Attending to the Needs of the Most Vulnerable

Nearly 50 percent of young children investigated by child welfare agencies are eligible for Part C services according to one study.³² Research finds that among children in child welfare, younger children (birth to 5) experience higher rates of developmental delays *and* are less likely to receive developmental interventions.³³ One study found that behavioral health difficulties were prominent among children under age 5 in child welfare (25-30%).³⁴ Even among 2-year-olds, the proportion with significant behavioral needs represented more than one-quarter of the population.³⁵ Among children with mental health needs, younger children (ages 2 to 3) were one-third as likely to access needed mental health services as their older counterparts in child welfare.³⁶ In the past, many child welfare agencies rendered different policies related to assessments of children with physical health conditions compared to those children with or at risk of mental health conditions or developmental delays. One study found that nearly one third of child welfare agencies had no policies in place that pertain to mental health or developmental assessments.³⁷ Only approximately three-fifths of child welfare agencies had assessment-related policies in place for children with developmental problems who were entering care, and only one-half had assessment-related policies for these children with mental health problems.³⁸ Even among agencies with comprehensive policies related to screening fewer than three-fifths were screened.³⁹

The knowledge base increasingly suggests that we should intervene earlier than at the time a child is diagnosed with a condition.⁴⁰ A young child's likelihood for poor outcomes increases with his or her risks exposure.⁴¹ Children with multiple risks are at increased risk for poor developmental outcomes. Eight states now allow at-risk criteria for eligibility for Part C.⁴² For those states that do not allow at-risk criteria, study investigators sought to determine the mechanisms available for children who did not meet the eligibility criteria to access services.

Leadership and Special Initiatives

The role of lead agencies, studies suggest, may impact other aspects of Part C administration and implementation. Thus examining whether lead agency status is a factor in states' approaches to supporting social-emotional wellbeing in their early intervention strategies became a key filter for the study's authors.⁴³ In addition, the authors examined states' eligibility categories related factors for being considered at-risk.

With the wide range of initiatives across government agencies and with private funding to address the needs of young children, coordination and collaboration across services programs, funding and policy streams becomes critical. One study found the lack of policy infrastructure supports compromised service integration and coordination necessary to facilitate ready access.⁴⁴ Indeed there is often the need to coordinate the coordinating entities. For this study, researchers assessed whether state Part C programs were involved in specific nationally or state-supported collaborative efforts, such as the Early Childhood Comprehensive Systems initiatives or the Assuring Better Child Health and Development (ABCD) Projects sponsored by the federal government and philanthropy respectively.⁴⁵

A descriptive analysis of the survey responses was conducted. The data were initially analyzed by frequencies. Additional analyses were conducted using three categories:

- ◆ the type of lead agency: the governor in each state identifies a lead agency responsible for the implementation of the Part C requirements. There are four types of lead agencies: Health; Education; Other State Agencies; and Co-Lead Agencies;
- ◆ the state eligibility status: The Office of Special Education Programs (OSEP) in the U.S. Department of Education has placed all states into three categories of eligibility; Broad, Moderate and Narrow; and
- ◆ at-risk eligibility: States with an eligibility definition that includes infants and toddlers with risk factors. The number of risk factors required varies by state.

A matrix of the states and their status in these categories is included in Appendix B. The survey responses were examined to see if the three categories were related to how states responded to the survey. Crosstab results for these three categories are only reported if there was a significant finding.

It is important to note that while 48 states responded to the survey, not all states answered every question. The number of states that answered each question is noted. Statistical adjustments were made to account for the changes in number of respondents.

PART 3

Study Findings

Section 1: Part C Screening, Referral and Evaluation Mechanisms

Policies and procedures regarding Screening, Referral and Evaluation are critical elements in the ability of an infant and toddler to access the early intervention system. Part C regulations require states to establish a Child Find and referral process designed to ensure the ability of families and referral sources to access the Part C system. Once infants and toddlers are referred to the system, some states will conduct screening activities to determine whether to move forward with a formal evaluation process, while other states begin the multidisciplinary evaluation process immediately.

Survey respondents were asked to identify tools that their state Part C systems recommended for screening infants and toddlers as a component of their Child Find system. The following tools were identified in the questionnaire:

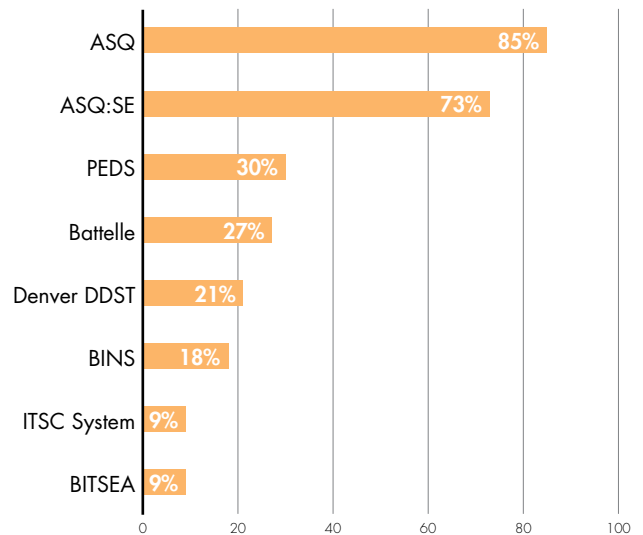
- ◆ Ages and Stages Questionnaire (ASQ);
- ◆ ASQ: Social-emotional (ASQ:SE);
- ◆ Battelle Developmental Screener;
- ◆ Bayley Infant Neurodevelopment Screener (BINS);
- ◆ Brief Infant-Toddler Social and Emotional Assessment (BITSEA);
- ◆ Denver DDST/Denver II;
- ◆ Infant Toddler Symptom Checklist (ITSC System); and
- ◆ Parents' Evaluation of Developmental Status (PEDS).

States were given the option to identify any other tools that they recommended. States could also identify that they do not make a formal recommendation.

Evaluation means the procedures used by appropriate qualified personnel to determine a child's initial and continuing eligibility under Part C. As part of that process, there must be a multidisciplinary evaluation of the child's level of functioning in each of the following developmental areas:

- ◆ cognitive development;
- ◆ physical development, including vision and hearing;
- ◆ communication development;
- ◆ social or emotional development; and
- ◆ adaptive development.

Figure 1: Screening tools states reported they recommend



All 48 states reported on whether they recommended a screening tool. Thirty-three (69%) of the states reported they recommended screening tools. Of those states that recommend a tool, twenty-eight (85%) recommend the ASQ and twenty-four (73%) also recommend the ASQ:SE. Twenty-three states (70%) recommended both the ASQ and ASQ:SE screening tools. Only three states (9%)

recommended the BITSEA and the ITSC System. Every identified screening tool was recommended by at least one state. Twenty-seven states (81%) recommended more than one screening tool. The number of screening tools that were recommended by states ranged from 1 to 7. Fifteen states (31%) indicated they do not recommend any specific screening tools.

States that responded they recommended “other screening tools” identified the following: Creative Curriculum Developmental Continuum Assessment; Work Sampling System; High Scope; Infant Development Inventory; Child Development Inventory; Early Learning Accomplishment Profile (ELAP); and Specific State tools developed as part of the ABCD II Initiative.

Part C coordinators reported on whether the Part C state agency was involved in efforts to promote screening by pediatric health care providers for

general development or social-emotional development. Forty-two of the 48 state Part C coordinators (88%) reported that they are participating in screening efforts by health care providers. One state did not know if there were screening efforts in place.

Figure 2: State participation in screening efforts

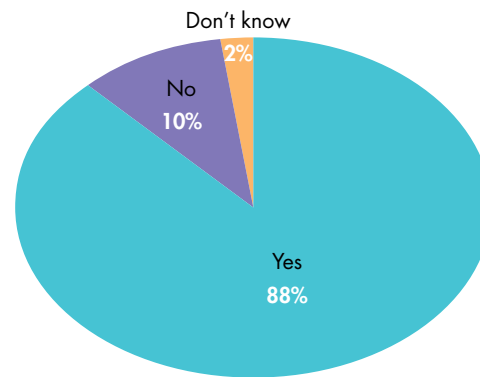


Table 1: Screening tools recommended by states

Screening tools	States
Ages and Stages Questionnaire (ASQ)	Alaska, Arizona, Colorado, Connecticut, Florida, Georgia, Hawaii, Idaho, Iowa, Kansas, Louisiana, Mississippi, Montana, Nebraska, Nevada, New Mexico, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, South Dakota, Texas, Utah, Vermont, Virginia, West Virginia, Wyoming
ASQ: Social-emotional (ASQ:SE)	Alaska, Arizona, Colorado, Connecticut, Delaware, Florida, Hawaii, Idaho, Iowa, Kansas, Montana, Nebraska, Nevada, New Mexico, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Texas, Utah, Virginia, West Virginia, Wyoming
Battelle Developmental Screener	Florida, Iowa, Maine, Montana, Nebraska, North Dakota, South Dakota, Tennessee, Virginia
Bayley Infant Neurodevelopment Screener (BINS)	Kansas, Maine, Nebraska, Nevada, North Dakota, Virginia
Brief Infant-Toddler Social and Emotional Assessment (BITSEA)	Kansas, North Dakota, Virginia
Denver DDST/Denver II	Mississippi, Montana, Nebraska, Ohio, South Dakota, Virginia
Infant Toddler Symptom Checklist (ITSC System)	Kansas, Montana, North Dakota,
Parents' Evaluation of Developmental Status (PEDS)	Arizona, Delaware, Iowa, Kansas, Montana, New Mexico, North Carolina, North Dakota, Oregon, Virginia
Other Tools	Alabama, California, Florida, Georgia, Hawaii, Iowa, Kansas, Kentucky, Maryland, Massachusetts, Michigan, New Hampshire, Pennsylvania, Rhode Island, Texas, Vermont

After screening has occurred, and a referral has been made to the state Part C system and evaluation completed, eligibility determination is the next step. To determine eligibility, the evaluation and assessment of each child must be conducted by personnel trained to utilize age- appropriate methods and procedures, including observations, use of standardized tools, health status information and parent input. Part C coordinators reported on the composition of the multidisciplinary team and whether it includes representation from a provider with social-emotional expertise.

All 48 states responded to this question. Twenty-seven states (56%) indicated that they did not require participation of a professional with social-emotional expertise on multidisciplinary evaluation teams. Only 16 states (34%) indicated that they required the participation of professionals in this discipline. One state encourages but does not require participation while two others indicated that participation depended on the needs of the child. Nine states provide training on this topic to all of the providers and use evaluation tools that are sensitive to the social-emotional domain.

States with Health as the Lead Agency are more likely to report that they include on the evaluation team a professional with social-emotional expertise. Only three states with “Other State Agencies” as the Lead and two states with Education as the Lead Agency require such expertise on the evaluation team.

Figure 3: Social-emotional expertise on evaluation teams

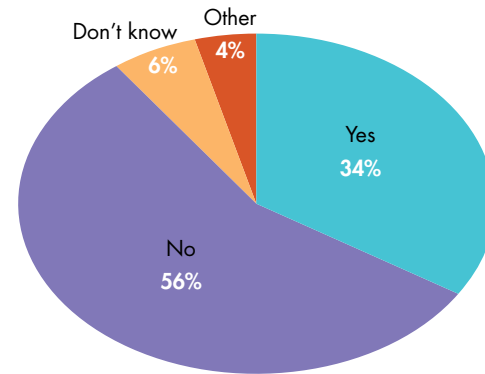
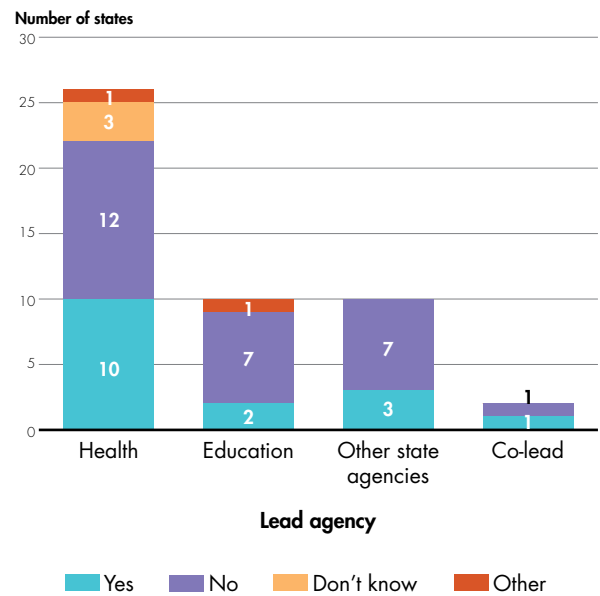


Figure 4: Participation on evaluation team by lead agency



Section 2: Services to Infants and Toddlers Eligible for Part C

Once eligibility for Part C is determined, the Part C system is required to develop an Individualized Family Service Plan (IFSP) that addresses the unique identified developmental needs of the eligible child and family. The Part C regulations (34 CFR §303.344) require that the IFSP include a statement of the child’s present level of physical, cognitive, communication, social-emotional and adaptive development. The IFSP must also include a statement of the services necessary to meet the specific needs of the child and family.

States are no longer required to report annually on the services provided under Part C. However, these data do suggest that Part C systems have traditionally focused on four of the 16 authorized services: Special Instruction and Occupational, Physical and Speech Therapy. Children at risk for social-emotional delay may need a different set of services than those provided to other eligible children.

Survey respondents reported on whether their state Part C systems permitted and financed four types of services: psychological or social-emotional testing and evaluation; infant and toddler relationship based dyadic or family therapy; group or

Early Intervention Services include, but are not limited to:

- ♦ assistive technology
- ♦ audiology
- ♦ family training, counseling and home visits
- ♦ health services
- ♦ medical services for diagnostic or evaluation purposes
- ♦ nursing services
- ♦ nutrition services
- ♦ occupational therapy
- ♦ physical therapy
- ♦ psychological services
- ♦ service coordination
- ♦ social work services
- ♦ special instruction
- ♦ speech-language pathology
- ♦ transportation
- ♦ vision

individual parent training targeted to parents of infants and toddlers, and respite care. Of the 48 states that answered this question, 35 states (73%) reported that they support group or individual

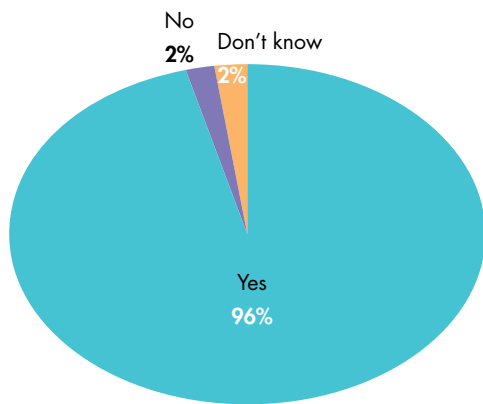
Table 2: Early intervention services to address social-emotional developmental delay in state Part C programs

Service	States
Psychological or social-emotional testing and evaluation	Alabama, Alaska, Arizona, California, Colorado, Delaware, Florida, Hawaii, Illinois, Indiana, Kansas, Louisiana, Maine, Maryland, Massachusetts, Minnesota, Mississippi, Missouri, Nevada, New Jersey, North Dakota, Oklahoma, Oregon, Rhode Island, South Dakota, Tennessee, Utah, Vermont, Virginia, Wyoming
Infant and toddler relationship based dyadic or family therapy	Alabama, Alaska, California, Colorado, Delaware, Hawaii, Idaho, Illinois, Indiana, Kansas, Louisiana, Maryland, Missouri, New Jersey, New Mexico, New York, North Carolina, North Dakota, Oklahoma, Pennsylvania, Rhode Island, Texas, Vermont, Virginia, West Virginia
Group or individual parent training targeted to parents of infants and toddlers	Alaska, Arizona, California, Colorado, Connecticut, Delaware, Florida, Georgia, Hawaii, Idaho, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maryland, Massachusetts, Mississippi, Missouri, Montana, Nebraska, Nevada, New Jersey, New Mexico, North Dakota, Ohio, Oklahoma, Pennsylvania, Rhode Island, Tennessee, Texas, Vermont, Virginia, West Virginia
Respite Care	California, Delaware, Idaho, Kentucky, Massachusetts, Nebraska, New Hampshire, New Jersey, New Mexico, New York, North Carolina, North Dakota, Texas, Utah, Vermont

parent training. Thirty states (63%) reported they supported psychological or social-emotional testing and evaluation. Twenty-five states (52%) indicated they support infant-toddler relationship training while only 15 states (31%) indicated they would support respite care. Although respite care is specifically included in a note in the Part C federal regulations,* it is not listed as one of the required 16 services. Family training and counseling as well as testing and evaluation are required services if the IFSP team determines these are needed based on the individual needs of the child and family.

Historically, State Part C systems did not gather data on the social-emotional wellbeing of infants and toddlers served through Part C. IDEA 2004 reauthorization required states to track child outcomes. To respond to this new requirement, the Office of Special Education Programs (OSEP) determined that each state must report on the percentage of infants and toddlers who demonstrate improved functional skills including those in the social-emotional domain. Annually, states monitor progress and report data in this area.

Figure 5: Data on improved social-emotional skills



Part C coordinators reported on whether they had data to measure performance on improved social-emotional skills. Forty-six of the 48 respondents indicated that they had data to measure progress in performance.

*34 CFR 303.12 (d)(Note)

Section 3: Services and Supports to At-risk, Non-eligible Infants and Toddlers

The 1986 enactment of P.L. 99-457 charged each Part C state system to establish criteria to determine which infants and toddlers would be eligible to receive services. Although language in the statute “encouraged” inclusion of children who are at risk of having substantial developmental delays if services are not provided, there was no requirement for inclusion of this population of children. With each Part C reauthorization, additional emphasis was placed on encouraging states to include children who are at risk and on requiring additional access of all children to Child Find and referral. With increasing numbers of children being served and decreasing state and federal funds, the number of states that had included at risk in their eligibility criteria has declined with only eight states and territories currently serving this population.

In light of the high number of states that do not include being at risk in their eligibility definitions, it is important to understand where families who are not eligible are being referred. State Part C Coordinators often report in informal discussions related to the Child Abuse Prevention Treatment Act (CAPTA) referrals that referrals of infants and toddlers who are at risk frequently result in a determination that the infants and toddlers do not meet the state’s eligibility criteria. It is important to determine where states refer families whose children do not meet the state’s eligibility criteria for Part C, but who clearly need services and supports.

Forty-five of the 48 states responded to the question on whether there were any written policies to guide referrals for infants and children who are considered at-risk in terms of social-emotional development, but not eligible for Part C. Seventeen states (38%) indicated they have written policies (regulations, policy guidance or provider manuals) to guide referrals to other community resources. Twenty seven states (56%) have no written policies.

Based on survey responses, states with narrow eligibility are more likely to have written policies than states with Broad or Moderate eligibility criteria. Eight states (50%) with Narrow Eligibility have written policies regarding referrals for infants and toddlers that do not meet Part C eligibility criteria.

Figure 6: Written policies for referral of non-eligible children

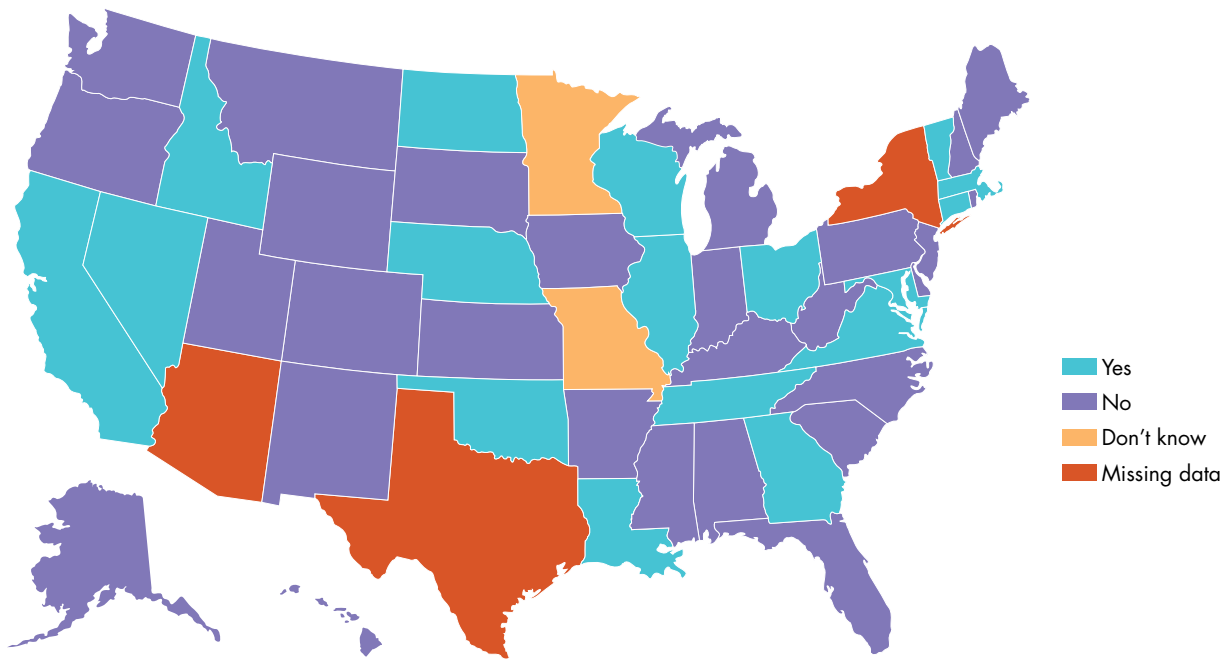


Figure 7: Written policies by eligibility

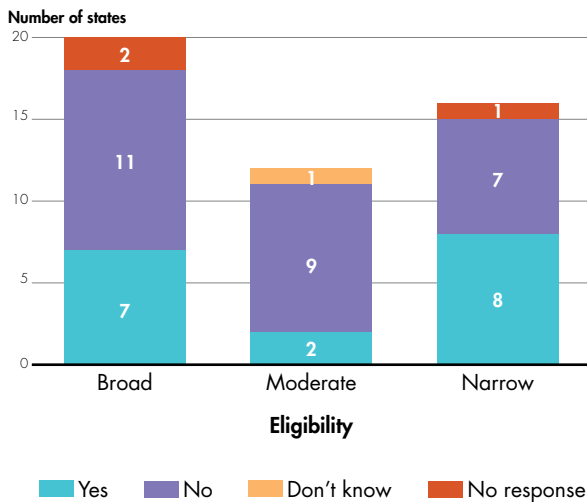
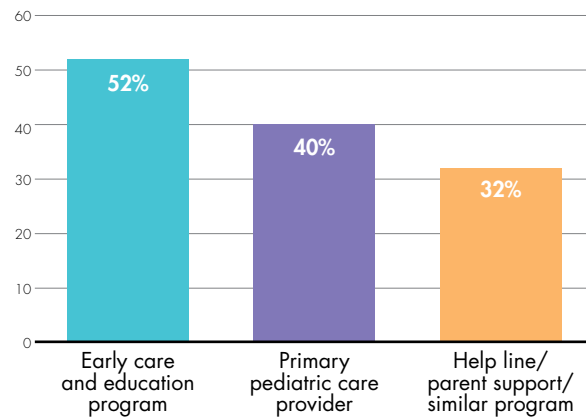


Figure 8: Programs to refer ineligible children



Of the 17 states with written policies, 13 (76%) refer ineligible children to Early Care and Education programs. Ten states (59%) refer children to a primary pediatric care provider and 10 states (59%) identified other community resources, such as surveillance programs, Children with Special Health Care Needs (CSHCN), local health departments and other community specific tracking programs. Eight

states (47%) refer ineligible infants and toddlers to a help line, parent support group or other similar programs. Seven states (41%) refer to all three of the identified resources. States with Health Lead Agencies more frequently refer ineligible children to their pediatric care provider than do their counterparts.

Section 4: Leadership and Special Initiatives

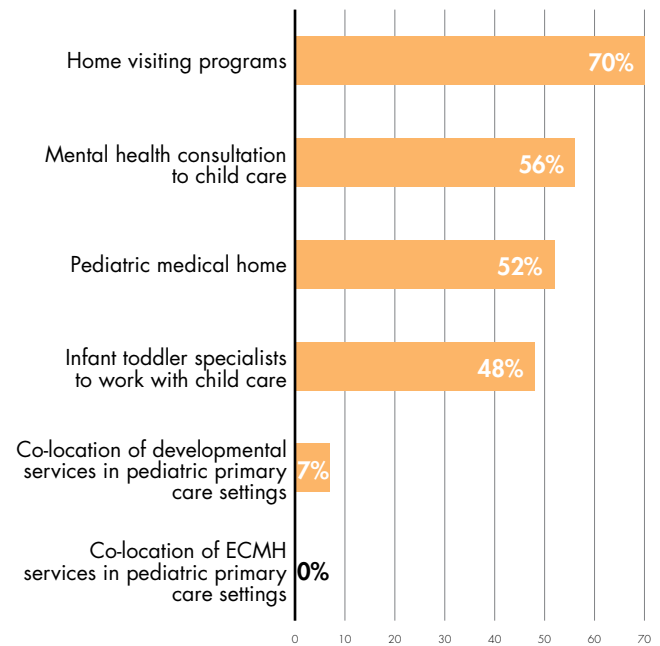
By Congressional design, Part C of IDEA was designed to be a coordinated, community-based, interagency system of services. Congress intended to build on already existing resources and foster connections through Part C across all of the different systems in which families of young children participate.

Survey respondents reported on whether they had developed a formal interagency agreement related to the CAPTA requirement for referral of children with substantiated cases of abuse and neglect to Part C. Twenty-four states responded to this question. Of those, 22 states (46%) have established formal interagency agreements related to infants and toddlers referred through CAPTA provisions and two states (4%) indicated they were in the process of developing formal agreements. Seventeen states (35%) that responded to this survey did not answer this question. Two states (4%) indicated they were developing formal agreements.

The 22 states that reported they have formal written interagency agreements were asked whether children are referred for screening in the Part C system or multidisciplinary evaluation. Nineteen of the 22 (86%) include referral for screening as part of the agreement. Each of the 22 states includes referral for a multidisciplinary evaluation. Sixteen states (73%) reported that infants and toddlers can be referred for evaluation without screening. Four states (18%) include referral for either screening or assessment.

Despite Congressional intent, some state Part C systems have historically operated as separate programs and have not been fully integrated into broader early childhood initiatives. The survey explored whether or not Part C systems have an explicit role in special initiatives in their states that address the infant and toddler population. The special initiatives identified were: early childhood mental health consultation to child care programs; infant and toddler specialists working with child care programs; state-based home visiting program; pediatric medical home initiative; and co-location of developmental services and/or early childhood mental health services in primary pediatric care settings.

Figure 9: Percentage of states reporting on their involvement in early childhood special initiatives by initiative type



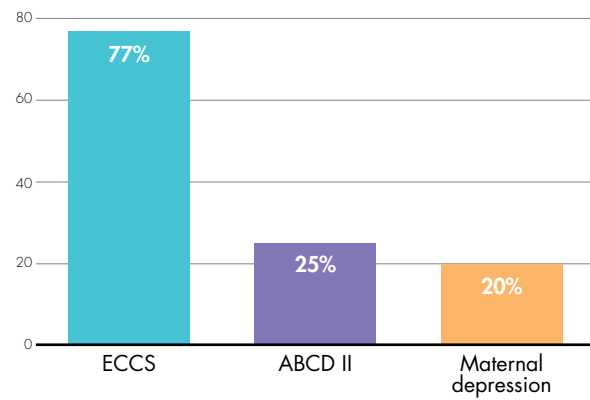
Twenty-seven states reported on the type of initiatives with which they were involved. Of those, the range of explicit involvement in these initiatives ranged from two states (7%) involved with co-location of developmental services in Pediatric Primary Care Settings to 19 states (70%) that indicated they were involved in home visiting programs. Fifteen states (56%) indicated they were not involved in any of these initiatives. States with Health as the Lead Agency had the highest percentage of involvement across all initiatives.

The survey also examined the involvement of state Part C systems in three national initiatives: Maternal Depression Projects, the Early Childhood Comprehensive Systems Initiative (ECCS) and the ABCD II Promoting Healthy Development Initiative.

Forty states reported on their involvement with national initiatives and indicated they have some involvement with at least one national initiative to improve outcomes for young children birth to 5. Thirty-one states (77%) indicated ECCS is the primary national initiative with which they are

involved. Ten states (25%) report they are involved with ABCD II and eight states (20%) are involved with maternal depression initiatives. Twenty states with Health as the Lead agency report their involvement with ECCS. This is consistent since state health departments are the leads for ECCS. Five of the states who extend eligibility to children who are at risk are involved with ECCS. Four states report they have no involvement with any initiative.

Figure 10: Percentage of states responding to this question



PART 4

Key Findings, Policy Implications and Recommendations

Summary of Findings

Screening and Assessments

A large majority of states (69%) recommend screening tools to detect developmental problems to clinicians. The most commonly recommended tools are the Ages and Stages Questionnaire (ASQ) and the Ages and Stages Questionnaire: Social-Emotional (ASQ:SE).

An overwhelming majority of states (88%) participate in efforts to promote screening by primary health care providers.

More than a third of states (34%) require the participation of a professional with social-emotional expertise on multi-disciplinary evaluation teams that determine eligibility for services.

Empirically Supported and Family Responsive Services

States were most likely to pay for group or individual parent training as part of the range of early intervention services available compared to respite care (73% vs. 31%). They also most frequently reported funding psychological or social-emotional testing and evaluation (63%). Only half of the states indicated they support infant-toddler relationship training.

Outcomes and Accountability

Nearly all states (96%) have statewide data to measure child performance regarding improved social-emotional skills.

Promotion of Wellbeing, Prevention of Ill Health, and Early Identification

Only eight states include children who are at risk as eligible for Part C services.⁴⁶ Although an additional

17 states have written policies to guide referrals for infants and children who are at risk in terms of social-emotional development, but not eligible for Part C.

Service Coordination and Service Enhancement especially for the Most Vulnerable Children

Service coordination among the various state and local initiatives that pertain to young children vary widely. Of the major local and national initiatives most states reported that they the Early Childhood Comprehensive System (ECCS) is the primary national initiative with which they are involved (77%) .

Half of all states have formal interagency agreements related to infants and toddlers in the child welfare system consistent with provisions in CAPTA. Of those, sixteen states reported that their agreement includes provisions for infants and toddlers to be referred to Part C for evaluation without prior screening.

Policy Implications

Support for Accurate Screening and Assessment

Research suggests a disconnect between the availability and use of accurate screenings and assessments. This study shows that a majority of states are recommending the use of standardized screening tools to detect potential problems with social-emotional developmental delays. The majority of states report they recommend the use of the standardized screening tools with the ASQ and ASQ:SE most frequently cited. Yet states also report a variety of additional screening tools that they recommend that are not standardized. Use of tools that lack accuracy may compromise states' efforts to improve the quality of early identification strategies, and may not be cost-effective. There is a clear need for state agencies and local communities to have expert

advice from the research community on the validity of the instrumentation.

Multidisciplinary evaluation teams form the nexus of the eligibility evaluation process yet less than two-fifths of states report that they require a professional with expertise in social-emotional development as part of the team. The absence of social-emotional development competency on the multidisciplinary evaluation team may explain the low prevalence to young children with social-emotional and behavioral problems in the Part C program. It may also be a factor in the disparities that research reveals between the number of children with identified social-emotional and behavioral developmental needs in the Part C system and reports from parents of young children both receiving early intervention services and those not deemed eligible for these services.

Support for Empirically-supported, Family Responsive Services

Applying the research base to services has increasingly gained attention. Effective prevention and treatment strategies are associated with improved outcomes for young children with developmental delays and those at risk of delays. The evidence also suggests some specific elements of effective strategies for young children and their families. Our study shows that while states support some intervention strategies with empirical support, other intervention strategies lack state funding and support. In particular, only half of the states included infant and toddler relationship-based dyadic or family therapy among their service array covered by Part C. Further, only one third of states supported respite in the Part C program. Nearly three-quarters of states support group or individual parent training that targets parents of infants and toddlers. These strategies fit within the core components of effective interventions. However without more information on the type of parenting program, it is difficult to gauge effectiveness. Research suggests that for children under age 3, group parenting programs may not be effective.⁴⁷

Support for Accountability and Outcomes Management to Support Service Quality

The movement towards accountability and outcomes management is likely to make data more widely available and has the potential to improve services quality and outcomes for young children enrolled in early intervention services. While this study showed that the U.S. Department of Education's Office of Special Education Programs (OSEP) requirement for data on functional improvement on social-emotional development will provide some longitudinal information, the indicator will report on all children in Part C and not separate the subgroup of infants and toddlers who were identified with social-emotional delay. To understand the progress states are making towards improving their Part C systems for young children with social-emotional problems, this data needs to be available. The data that OSEP collects from states will also be missing the group of at-risk infants and toddlers who do not meet the state's eligibility criteria.

Support for Promotion of Wellbeing, Prevention of Ill Health

Notable changes in the approach to early intervention services in recent decades are the application of research to the framework for service provision and their policy supports and, the focus on promotion of child development and prevention of developmental problems.⁴⁸ Under IDEA, states are encouraged to provide avenues to access services for children who are at risk of developmental delays if they do not qualify for early intervention services. Yet, there are no federal requirements in Part C to refer infants and toddlers that are not eligible for services to other community resources. This study found that only 17 states have written policies that guide their approach to referrals for children who are at risk for developmental delays but not eligible for services. However given the vulnerability of these children, it is critical that states and communities have policies and/or procedures that will support the identification of other community resources for which the children may be eligible. There is a great need for high quality services for this population of infants and toddlers at risk for social-emotional delay, as well as for their families, who clearly need services and supports but who will not receive them under Part C.

Support for Service Enhancement and Coordination, Especially for the Most Vulnerable Children

With the exception of the ECCS initiative, there is an apparent lack of involvement of state Part C systems in the broader early childhood initiatives. This may be an indication of the competing priorities facing Part C coordinators and the multiple systems focused on young children and their families that have emerged.

Study Limitations

There are several limitations with this study. First, the survey did not include questions regarding funding sources. Exploring more completely the types of funding used by Part C systems will help to understand the role that Title XX (Medicaid), Title V (Maternal and Child Health) as well as other federal and state fund sources (both public and private) play in supporting the provision of services to infants and toddlers with social-emotional delays. Second, this survey did not ask about assessment and evaluation tools used within the state. Study investigators are aware of many discussions among Part C coordinators that the evaluation tools that providers use may lack sufficient sensitivity to identify a percentage of delay or standard deviation in the social-emotional domain that is required for eligibility determination. Without an assessment tool that has a high degree of accuracy related to the social-emotional domain, the absence of a provider with social-emotional expertise on the multidisciplinary evaluation team creates a vulnerability for children who may actually meet the eligibility criteria but lack the documentation and expertise to support eligibility determination. Given the difficulty with the instrumentation, the expertise of the provider may support eligibility determination based on informed clinical opinion.

Recommendations

Screening and Assessments

- ◆ For clinicians and others who make eligibility determinations and provide services at the child and family level, states should support the use of, and the federal government should encourage and fiscally incentivize where possible, valid instruments for screening and assessment of infants and toddlers at risk for social-emotional developmental delay.
- ◆ When screening infants and toddlers for developmental delay, valid, multi-domain screening tools that are also designed to identify problems in the social-emotional domain should be used, such as the Infant-Toddler Development Assessment (IDA). Alternatively, a general screening tool should be supplemented by using a screening tool designed specifically for the social-emotional domain, such as the ASQ:SE.
- ◆ States and the federal government should support – through funding if necessary – high quality training and technical assistance to ensure implementation fidelity of the existing valid screening and assessment tools for clinicians and others involved in eligibility determinations and who provide treatment and supports at the child and family level.

Empirically-Supported and Family Responsive Services

- ◆ States, the federal government, and tribal jurisdictions should, through funding and by ensuring them as part of benefit sets, support the availability of empirically supported and family responsive services to meet the needs of young children with social-emotional developmental delays or at risk for such delays. Minimally, all states should be required to provide, where clinicians indicate the need, access to a range of evidence-based interventions and support for young children. In particular, relationship-focused dyadic infant and toddler interventions should be available in the service array of state Part C programs.
- ◆ States, the federal government and tribal jurisdictions should undertake training and technical

assistance to support the widespread adoption of evidence-based or empirically supported interventions to address the social-emotional developmental needs of young children eligible for Part C programs and for clinicians to whom young children at risk for developmental delays are referred.

Outcomes and Accountability

- ◆ The United States Education Department, Office of Special Education Programs (OSEP) should publicly and annually report on indicators for social-emotional wellbeing for children with social-emotional developmental delays who receive services through the Part C program.
- ◆ OSEP should develop targets for increasing the availability of services to address the social-emotional developmental needs of young children served in the Part C program.
- ◆ OSEP should report on indicators for social-emotional wellbeing for children who receive services through the Part C program by race and ethnicity, in light of the evidence of the disparities in access to needed services previously documented.⁴⁹

Promotion of Wellbeing, Prevention of Ill Health, and Early Identification

- ◆ States, OSEP and tribal jurisdictions should report on those children deemed at risk of a social-emotional developmental delay who do not meet the eligibility criteria for Part C.
- ◆ OSEP, working in concert with states, should develop guidelines for how and where to refer children who are at risk and do not meet eligibility criteria.
- ◆ States, tribal jurisdictions and OSEP should track and report referrals for children deemed at risk for social-emotional developmental delay who do not meet the eligibility criteria for Part C.

Support for Service-enhancement and Service Coordination especially for the most Vulnerable Children

- ◆ Policies and financial resources at the federal, state and tribal jurisdictional level should be better coordinated and aligned to support cross-agency planning, implementation and evaluation of resources and supports to adequately address the needs of infants and toddlers and their families. The federal government and states should place a moratorium on the creation of additional coordinating bodies and improve and work through existing efforts to meet the need for services integration and coordination.
- ◆ Federal policy and resource allocation should be designed to ensure that all young children receive the resources and supports that they need.

The Need for More Information

- ◆ The federal government should underwrite a study to identify all potentially available federal, state, public and private resources to support screening, evaluation and service delivery for young children with or at risk for social-emotional developmental delay.
- ◆ The federal government, in partnership with private groups, should support research and dissemination of valid and reliable instruments for screening and assessment and ensure that these are culturally competent and appropriate to infants and toddlers.

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APPENDIX A1

Survey of State Part C Agencies Regarding Screening and Services for Social-Emotional Development

NCCCP National Center for
Children in Poverty
Columbia University
MAILMAN SCHOOL OF PUBLIC HEALTH

215 West 125th Street, 3rd floor
New York, NY 10027-4426
Tel: 646.284.9600
Fax: 646.284.9623
www.nccp.org

Survey of State Part C Agencies Regarding Screening and Services for Social-Emotional Development

Please email completed survey by Jan. 26th
to: feldstein@nccp.org

or fax to: **646-284-9660**

or mail to: Lisa Feldstein
NCCP, 215 W. 125 Street, 3rd flr.
New York, NY 10027

NOTE: The free Acrobat Reader will not allow you to save completed forms. If you are using Acrobat Reader, you must fill in and print your forms in a single session and either mail or fax them to us. If you have purchased the full version of Acrobat software, you can fill in the form, save it, and email it to us.

Part C Survey for
[state name]

A PART C SCREENING, REFERRAL, AND EVALUATION MECHANISMS

1. Each state's Child Find system is responsible for locating infants and toddlers who are in need of and potentially eligible for Part C services. What strategies does your state Part C program use for outreach to and identification of infants and toddlers? (Check all that apply.)

- Outreach (beyond informational brochures) to
 - Community pediatricians
 - Child care and early education providers
 - Child protective services (CPS) and child welfare workers
- Public awareness campaigns about early intervention
- Information from population-based registries (e.g., vital statistics, newborn screening)
- Community-based screening efforts (e.g., health fairs, screening days)
- Other (please specify) _____

2. Part C federal rules call for states to have methods in place that primary referral sources can use for referring a child for evaluation and assessment. Does your state Child Find have a standard referral form or procedure to be used by the following referral sources? (Check all that apply.)

- Hospitals, including perinatal care facilities
- Physicians and other primary health care providers
- Parents/families
- Early care and education programs (e.g., child care, Early Head Start)
- Local educational agencies
- Public health clinics and programs (e.g., local health department, WIC)
- Child welfare and CPS agencies
- Other (please specify) _____

3. Does the Part C agency routinely conduct multidisciplinary assessments based on screening and referral by the following providers? (Check all that apply.)

- Physicians and other health care professionals, including staff in NICUs
- Early care and education programs (e.g. child care, Early Head Start)
- Community-based screening efforts (e.g., health fairs, screening days)
- Other (please specify) _____

4. Is the Part C state agency involved in efforts to promote developmental screening by pediatric primary care providers?

- Yes No Don't know

If yes, is Part C involved in efforts to promote primary care screening for: (Please check one.)

- General developmental screening
- Social-emotional development screening
- Both general development and social-emotional development

5. Does the Part C agency in your state recommend any of these standardized screening tools to Child Find providers? (Check all that apply.)

- | | |
|--|--|
| <input type="checkbox"/> Ages and Stages Questionnaire (ASQ) | <input type="checkbox"/> Brief Infant-Toddler Social and Emotional Assessment (BITSEA) |
| <input type="checkbox"/> ASQ: Social-Emotional (ASQ: SE) | <input type="checkbox"/> Denver DDST/Denver II |
| <input type="checkbox"/> Battelle Developmental Screener | <input type="checkbox"/> Infant-Toddler Symptom Checklist |
| <input type="checkbox"/> Bayley Infant Neurodevelopment Screener | <input type="checkbox"/> Parents' Evaluation of Developmental Status (PEDS) |
| <input type="checkbox"/> Other (please specify) _____ | |

B SERVICES TO INFANTS AND TODDLERS ELIGIBLE FOR PART C

6. Early intervention services include psychological services, but states vary in their definition of such services. Does your state Part C program cover and finance the following specific services under Individualized Family Service Plans (IFSPs)? (Check all that apply.)

- Psychological counseling for infants and parents together (i.e., family counseling)
- If yes, does this explicitly include infant and toddler relationship-based dyadic or family therapy?
- Yes No Don't know
- Group or individual parent training
- Respite care

7. Does your state have data to measure performance on the required indicator on the percent of infants and toddlers with IFSPs who demonstrate improved positive social-emotional skills (including social relationships)?

- Yes No Don't know

8. In which of the following ways does your state Part C program link to health providers?

- Require pediatric provider's signature on the IFSP
- Reimburse pediatric providers for participation in IFSP meetings
- Require health status assessment as part of the Part C multidisciplinary assessment
- Other (please specify) _____

9. Has your state Part C program taken action to strengthen professional skills in response to emerging science about the importance of early relationships and social-emotional development? (Check all that apply.)

- Train Part C providers on the importance of early social-emotional development
- Require multidisciplinary evaluation teams to include professionals with expertise in infant and toddler social-emotional normal and atypical development
- Contract with IFSP service providers with expertise in infant and toddler mental health
- Other (please specify) _____

C SERVICES AND SUPPORTS TO AT-RISK BUT NOT ELIGIBLE INFANTS AND TODDLERS

Under federal law, states may use Part C funds to collaborate with public or private community-based organizations to identify, make referrals for, and conduct follow-up with at-risk infants and toddlers. The following questions ask about those at-risk infants and toddlers *not* eligible for Part C.

10. Does your state have any mechanisms to track or monitor the development of infants and toddlers *at risk* but *not* eligible for Part C?

- Yes No Don't know

11. If Part C finds *ineligible* infants and toddlers that are considered "*at-risk*" in terms of social-emotional development, are there any written policies and/or procedures (e.g., in regulations, policy guidance, provider manuals) to guide referrals to: (Check all that apply.)

- Primary pediatric care provider
- Help line, parent-support, or other similar program
- Early care and education program (e.g., Early Head Start, a home-visiting program)
- Program to address early childhood social-emotional/mental health needs
- Other (please specify) _____

12. Is there a statewide program to provide services to infants, toddlers, and families who have identified risks but are not eligible for Part C?

- Yes No Don't know

D INTERAGENCY MECHANISMS

13. Has your state implemented the Child Abuse Prevention and Treatment Act (CAPTA) requirement for referring children with substantiated cases of abuse and neglect to the Part C system for evaluation statewide?

- Yes, statewide Yes, in parts of state No Don't know

If yes, are eligible children referred directly for multidisciplinary assessment without screening?

- Yes Don't know

- No. We require screening carried out first by: (Check all that apply.)
 - Child welfare agency
 - Part C agency
 - Third party provider
 - Other _____

14. Does your state have specific guidance to determine who pays for what services when children are eligible under both Medicaid and Part C?

- Yes No Don't know

15. In the box below, please check all that apply in your state for Part C cooperation with other agencies, e.g., if Part C has an interagency financing agreement or transfer in place with Medicaid, put a check in the Medicaid box.

	Joint referral processes or forms	Joint eligibility processes or forms	Interagency finance agreements	Integrated service plans
Medicaid	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Title V MCH or CSHCN	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mental Health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Child Welfare/Children's Services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

E LEADERSHIP AND SPECIAL INITIATIVES

16. Does the Part C program have a formal role (e.g., use for outreach and referrals, encourage local system linkages, provide funding) in state initiatives related to: (Check all that apply.)

- Early childhood mental health consultation
- State-based home-visiting programs
- Pediatric medical home
- Colocation of developmental services in pediatric primary care settings
- Colocation of early childhood mental health services in pediatric primary care settings
- Other (please specify) _____

17. Is the Part C agency involved in any of the following state initiatives to improve outcomes for young children birth to age 5 who are at risk for poor social-emotional outcomes? (Check all that apply.)

- ABCD II Promoting Healthy Mental Development
- Early Childhood Comprehensive Systems (ECCS) initiative
- BUILD early childhood initiative
- Maternal depression project or initiative
- Other (please specify) _____

18. Does your state Part C program:

- Lead or participate in a state initiative (e.g., fiscal planning, cross-training, etc.) to promote healthy social-emotional development in infants and toddlers
- Routinely seek input from professional health organizations (e.g., American Academy of Pediatrics)
- Share information with the Title V Program for Children with Special Health Care Needs

Note: If your state has special Part C program efforts related to: infants and toddlers with or at risk for social and emotional problems, promoting better links with primary care physicians, and/or implementing CAPTA that you believe could or should be replicated in other states, please describe below.

Survey of State Part C Agencies Regarding Screening and Services

1. Part C Screening, Referral, and Evaluation Mechanisms

1. Please indicate which state you represent.

State: ▼

2. Does Part C in your state recommend any of these standardized screening tools to Child Find or other screen providers? (Check all that apply.)

- Part C does not recommend any of these standardized screening tools.
- Ages and Stages Questionnaire (ASQ)
- ASQ: Social-Emotional (ASQ: SE)
- Batelle Developmental Screener
- Bayley Infant Neurodevelopment Screener (BINS)
- Brief Infant-Toddler Social and Emotional Assessment (BITSEA)
- Denver DST/Denver II
- Infant-Toddler System Checklist
- Parent's Evaluation of Development (PEDS)
- Other (please specify)

3. Is the Part C state agency involved in efforts to promote screening by pediatric primary health care providers (pediatricians, family physicians, nurse practitioners, etc.) for general development or social-emotional development?

- Yes
- No
- Don't Know

Other (please specify)

4. Federal law calls for a timely, comprehensive, multidisciplinary evaluation of each infant or toddler referred to Part C. Does your state Part C program require that multidisciplinary evaluation teams include professionals with expertise in infant and toddler social-emotional development or infant mental health?

- Yes
- No
- Don't Know

Other (please specify)

Survey of State Part C Agencies Regarding Screening and Services

2. Services to Infants and Toddlers Eligible for Part C

5. The federal Part C State Performance Plan (SPP) monitoring priorities include an indicator on the percent of infants and toddlers with IFSP's who demonstrate improved positive social-emotional skills (including social relationships). Does your state currently have data to measure performance on this indicator?

- Yes
 No
 Don't Know

Other (please specify)

6. Part C early intervention services include psychological services, but states vary in their definition of such services. Does your state Part C program permit and finance the following specific services under Individualized Family Service Plans (IFSPs)? (Check all that apply.)

- State Part C program does not permit and finance these services under IFSPs.
 Psychological or social-emotional testing and evaluation
 Infant & toddler relationship based dyadic or family therapy
 Group or individual parent training targeted to parents of infants and toddlers
 Respite care

Other (please specify)

3. Services and Supports to At-Risk but Not Eligible Infants and Toddlers

Under federal law, states may use Part C funds to collaborate with public or private community-based organizations to identify, make referrals for, and conduct follow-up with *at-risk* infants and toddlers. The following two questions ask about those at-risk infants and toddlers not eligible for Part C.

7. If infants and toddlers are "at-risk" in terms of social-emotional development but not eligible for Part C, are there any written policies to guide referrals (e.g., in regulations, policy guidance, provider manuals)?

- Yes
 No
 Don't Know

Other (please specify)

Survey of State Part C Agencies Regarding Screening and Services

8. If you answered YES to the question above, are there policies and/or procedures for referring ineligible child/family to:

- Primary pediatric care provider
- A help line, parent-support or other similar program
- An early care and education program (e.g., Early Head Start, a home-visiting program)
- Other (please specify)

4. Leadership and Special Initiatives

9. IDEA and the Child Abuse Prevention and Treatment Act (CAPTA) require that children with substantiated cases of abuse and neglect be referred to Part C for evaluation statewide. In implementing these requirements, has your state developed formal interagency agreements?

- Yes
- No
- Don't Know

Other (please specify)

10. If you answered YES to the question above, what is the child referred for? (Check all that apply.)

- Screening in Part C system
- Multidisciplinary evaluation in Part C system
- Other (please specify)

Survey of State Part C Agencies Regarding Screening and Services

11. Does Part C have an explicit role in special initiatives related to the following: (e.g., are there provisions for Part C outreach and referrals, does Part C participate in funding, and so forth) (Check all that apply.)

- Part C does not have an explicit role in these types of initiatives.
- Early childhood mental health consultation to child care programs
- Infant and toddler specialists to work with child care programs
- State-based home-visiting programs
- Pediatric medical home initiatives
- Co-location of developmental services in pediatric primary care settings
- Co-location of early childhood mental health services in pediatric primary care settings

Other (please specify)

12. Is Part C involved in any of the following state initiatives to improve outcomes for young children birth to five?

- Part C is not currently involved in any of these state initiatives
- ABCD II Promoting Healthy Mental Development
- Early Childhood Comprehensive Systems (ECCS) initiative
- Maternal depression project or initiative
- Other (please specify)

13. We have support for a number of brief case studies of state Part C program efforts to provide services to children with delays in or risks for social-emotional development. Would you be willing to participate in an interview if your state were selected?

- Yes
- No

14. If YES, please enter your contact information.

Name:

Agency:

State: ▼

Email Address:

Phone Number:

Survey of State Part C Agencies Regarding Screening and Services

15. Please write any additional comments that you think may be helpful for us in understanding your state's screening and services for social-emotional development.

APPENDIX B

State Part C Programs by Lead Agency, Eligibility and At Risk Status

STATE	Lead agency				Eligibility			At risk Serves at risk
	Health	Education	Other state agency	Co-lead	Broad	Moderate	Narrow	
ALABAMA			✓		✓			
ALASKA	✓					✓		
ARIZONA			✓				✓	
ARKANSAS	✓				✓			
CALIFORNIA			✓		✓			✓
COLORADO			✓			✓		
CONNECTICUT			✓				✓	
DELAWARE	✓					✓		
FLORIDA	✓				✓			
GEORGIA	✓						✓	
HAWAII	✓				✓			✓
IDAHO	✓						✓	
ILLINOIS	✓					✓		
INDIANA			✓			✓		
IOWA		✓			✓			
KANSAS	✓				✓			
KENTUCKY	✓					✓		
LOUISIANA	✓						✓	
MAINE		✓					✓	
MARYLAND		✓			✓			
MASSACHUSETTS	✓				✓			✓
MICHIGAN		✓			✓			
MINNESOTA		✓				✓		
MISSISSIPPI	✓				✓			
MISSOURI		✓					✓	
MONTANA	✓						✓	
NEBRASKA				✓			✓	
NEVADA	✓						✓	
NEW HAMPSHIRE	✓				✓			✓
NEW JERSEY	✓				✓			
NEW MEXICO	✓				✓			✓
NEW YORK	✓				✓			
NORTH CAROLINA	✓					✓		
NORTH DAKOTA			✓				✓	
OHIO	✓				✓			
OKLAHOMA		✓					✓	
OREGON		✓					✓	
PENNSYLVANIA			✓		✓			
RHODE ISLAND			✓			✓		
SOUTH CAROLINA	✓						✓	
SOUTH DAKOTA		✓				✓		
TENNESSEE		✓					✓	
TEXAS			✓		✓			
UTAH	✓						✓	
VERMONT				✓	✓			
VIRGINIA	✓				✓			
WASHINGTON	✓				✓			
WEST VIRGINIA	✓				✓			✓
WISCONSIN	✓				✓			
WYOMING	✓				✓			