



## PART C ADMINISTRATOR IMPLEMENTATION TECHNICAL ASSISTANCE GUIDE

# DEVELOPMENTAL MONITORING, SCREENING, AND REFERRAL

### INTRODUCTION

The Individuals with Disabilities Education Act (IDEA) requires State Part C lead agencies to have a comprehensive child find system. The child find system must have referral procedures in place so that parents; health care providers, such as pediatricians; social services agencies; early childhood educators; and other individuals can refer children to IDEA Part C if there are concerns about their development. As part of their work with young children, these providers and programs regularly use developmental monitoring and conduct developmental screenings to assess if children are meeting developmental milestones. They therefore are key partners in working with IDEA Part C programs to identify infants and toddlers who may have disabilities or delays in development, and then connecting families to IDEA Part C for further assessment.<sup>1</sup>

### IDEA PART C STATUTORY AND REGULATORY KEY PRINCIPLES

- Comprehensive child find system
- Early and appropriate identification of all eligible children, including from underserved groups
- Coordination among agencies and early childhood programs
- Outreach to and engagement with families and primary referral sources
- Promoting development, learning, and school readiness

IDEA sections 632, 634, 635(a)(1)-(8), 636(a), and 637(a)(3)-(7) and 34 C.F.R. Part 303. Second level

### DEVELOPMENTAL MONITORING

Physicians, other health care providers, and early childhood educators regularly use developmental monitoring, an informal practice of observing young children's development and listening to families' concerns about their children's development, to see how children are meeting developmental milestones. Developmental monitoring does not require standardized tools, but those conducting the observations should be knowledgeable about childhood milestones and how to identify a child not reaching those milestones. The American Academy of Pediatrics' Bright Futures Guidelines for Health Supervision of Infants, Children, and Adolescents offers an excellent model for monitoring and surveillance practices, and the Center for Disease Control and Prevention's Learn the Signs, Act Early tools can help families and providers, including those from diverse cultural and linguistic backgrounds, monitor young children's development. Developmental monitoring can increase families' knowledge and skills for promoting their child's development and support them in understanding when to be concerned and when to share concerns with a provider.<sup>2</sup>

# INTRODUCTION

## DEVELOPMENTAL SCREENING

*Developmental screening* includes administering a validated and standardized test or questionnaire to assess and help determine more accurately if a child is developing within a range expected for most children of the same age.<sup>3</sup> The American Academy of Pediatrics (AAP) recommends that developmental screening be a regular part of well-child visits for all children at 9, 18, and 30 months of age, with autism specific screening at 18 and 24 months, with the option that these screenings can occur more frequently for some children when there is a developmental concern.<sup>4</sup> While IDEA includes requirements for when State lead agencies conduct screening for Part C services, most developmental screenings occur through primary referral sources.

## REFERRAL

If developmental concerns are noted by physicians, other health care providers, and early childhood educators, Part C regulations require the State to have procedures to refer, within seven days of identification, parents to the IDEA Part C program in their State for an evaluation to determine if their infant or toddler is eligible for services under IDEA Part C. Parents may also contact IDEA Part C programs directly to request an evaluation for their child. Studies have shown that parents and health care providers are the most frequent<sup>5</sup> and reliable<sup>6</sup> referral sources to IDEA Part C. Early childhood providers have also been shown to be important partners in referring infants and toddlers with developmental concerns to Part C.<sup>7</sup>

While States are required to have child find systems in place, many families still encounter barriers to accessing developmental screening and referral to IDEA Part C for their infants and toddlers. First, many young children do not receive regular screening through well-child visits despite the AAP recommendations. One study found that only a little more than 30 percent of infants and toddlers received a parent-completed developmental screening, and 37 percent received developmental surveillance from a health care professional in a single year.<sup>8</sup> Even when developmental screening is broadly implemented, data shows that not all infants and toddlers who should be referred are referred.<sup>9</sup> There are several challenges contributing to these barriers. One challenge is a lack of providers who have the knowledge to conduct developmental screenings. Additionally, health care providers can encounter challenges finding time to conduct relevant screenings and complete referrals, as well as confusion and uncertainty related to receiving reimbursement for screening services performed.<sup>10</sup> Infrastructure for coordinating care across providers is often lacking or difficult to navigate.<sup>11</sup> Lack of understanding of key components of the IDEA Part C system, such as who the IDEA Part C program contacts are, how to contact providers in the State or community, how to refer a family, or what services the IDEA Part C program offers, can also be a barrier.<sup>12</sup> Additionally, primary referral sources often are hesitant to refer children who do not appear to have noticeably significant delays even though they may benefit from such services.



# CASE STUDY: HOW A MONITORING SYSTEM IMPACTED CHILDREN THROUGHOUT NEBRASKA

The University of Nebraska has implemented one of the only statewide Newborn Intensive Care Unit (NICU) follow-up programs in the United States. Offered free to all eligible families in the State, the Developmental Tracking Infant Progress Statewide (TIPS) program follows babies born prematurely and/or who have had a NICU experience to identify delays in their development.

Participants are enrolled into the program through a pediatrician, nurse, social worker, or other staff whom they encounter in the NICU. The program includes regular and ongoing assessments of the children to monitor their progress and development using various screening tools, as determined by the extent of their prematurity, complexity of their medical history, and/or the results of preliminary hearing and vision screenings. Data are tracked to monitor the progress of children over time. TIPS specialists are trained to make referrals for follow-up appointments or additional services to address any delays that are identified through assessments conducted through Nebraska's Early Development Network. TIPS specialists also provide ongoing counseling and guidance to parents about how to monitor their children's development and support continued growth at home. Assessments are provided to children through the program up until age 3. Since 2000, Developmental TIPS has successfully enrolled more than 1,000 children for IDEA Part C services in Nebraska.

## STRATEGIES IN ACTION: ENSURING REGULAR OUTREACH TO REFERRAL SOURCES INCREASED PART C ENROLLMENT

In its 2021 Annual Report to the Legislature, Maine's State Director of Child Development Services (CDS) reported an expanded and systematic statewide outreach campaign to primary referral sources across the State. The State had traditionally reported one of the lowest child find rates and some of the narrowest eligibility criteria in the country.

The State released an outreach plan that identified a list of primary referral sources (i.e., primary care physicians, audiologists, home health agencies) that needed to be contacted by each regional CDS site annually. They also released an updated list of established conditions that make children under age 3 automatically eligible for early intervention and communicated these changes through remote meetings and trainings across agencies with primary referral sources.

As a result, from federal fiscal year (FFY) 2019 to FFY 2020, Maine's Part C enrollment increased 81% for infants (birth to 1) and 19% for toddlers (1- to 2-year-olds), with an overall increase of 22% (birth through age 2). The State also experienced a 22% increase in the total number of children with individual family service plans.



# STRATEGIES

State Part C administrators can apply research-supported approaches to support high-quality monitoring, screening, and referral within their States to equitably locate, identify, and refer infants and toddlers in need of IDEA Part C services by implementing the following strategies:

## PROMOTE UNIVERSAL DEVELOPMENTAL MONITORING AND SCREENING

Developmental monitoring and screening to detect developmental delays or disabilities should occur as part of both newborn<sup>13, 14, 15</sup> and regular well-child visits.<sup>16, 17</sup> The [CDC](#) offers a list of resources for conducting monitoring and screening as does the [Early Childhood Learning and Knowledge Center \(ECLKC\)](#), operated by the Office of Head Start. Part C administrators should partner with health care and early childhood providers to develop campaigns and resources to encourage and support providers in incorporating both developmental monitoring and developmental screening within their practice.<sup>18</sup> Part C administrators should also track screening rates within their States and among subgroups to target campaigns and resources toward reaching underserved infants and toddlers.

## PROMOTE USE OF VALIDATED SCREENING TOOLS IN MULTIPLE DOMAINS

Tools designed with a strong foundation of research can promote appropriate referrals based on accurate screening results (see Resource for Support for more information). The AAP recommends that screening tools address four developmental domains: (1) fine and gross motor skills, (2) language and communication, (3) problem-solving and adaptive behavior, and (4) personal-social skills.<sup>19</sup> Tools should be validated with, and appropriate for, culturally and linguistically diverse populations. A [Community of Learning \(COL\) approach](#), which authentically engages specific communities to assess their needs, applies these needs toward the design and selection of tools and interventions, and supports the inclusion of children from culturally and linguistically diverse backgrounds within early childhood programs, can support communities in using strong screening practices.

## TRAIN EARLY CHILDHOOD PROVIDERS IN MONITORING, SCREENING, AND REFERRAL

Staff in early childhood programs should understand child development and be aware of how to conduct developmental monitoring, at what age screenings should occur, and where to refer families if there are developmental concerns.<sup>20</sup> Part C State administrators and those of other early childhood programs should make ongoing professional development opportunities available for child care providers, home visitors, and other early childhood providers to understand developmental monitoring and screening, the use of evidence-based screening tools, how to talk with families about developmental screening results, and how to support families in the referral process to IDEA Part C. The AAP offers videos on [developmental surveillance](#) and [monitoring](#) to support this learning. The Office of Head Start has a [brief](#) on developmental screening and an [infographic](#) on children with disabilities and IDEA services that can be used by early childhood providers. States should also ensure shared use and understanding of screening results across Early Head Start and IDEA Part C agencies so that families do not have to duplicate the screening process if referred to IDEA Part C.



# STRATEGIES

## ENSURE HEALTH PROVIDERS UNDERSTAND PART C SERVICES AND THE REFERRAL PROCESS

Health care providers need to have an understanding of what IDEA Part C services are, the potential benefits of Part C services, how infants and toddlers become eligible for services, points of contact to refer children to or to get information on the program, and their role and their organizations' practices in the referral process so that they can make well-informed decisions on referring families. State Part C administrators should specifically work with health care providers to understand the established conditions in the State in which infants and toddlers are automatically presumed eligible for early intervention services in addition to the State's definition for developmental delay. Additionally State Part C administrators should work with health care providers to develop messaging on referral to IDEA Part C, a universal referral form to refer to IDEA Part C, and how to convey this information and provide training to other health care providers. The messaging should include the importance of connecting young children as early as possible with not only Part C but also other available services such as home visiting programs. Engagement with health care providers should go beyond pediatricians to include nurse practitioners, physician assistants, and family care providers.

## IMPLEMENT MEASURES TO SUPPORT SCREENING AND REFERRAL FOR FAMILIES

State Part C administrators should work with primary referral sources on how to effectively support families in the referral process. When a referral is made, health care and early childhood providers should be able to discuss the referral process and next steps in a way that is culturally and linguistically responsive so that families can understand the process, know what to expect, and are clear about how to get support along the way. Patient navigators, who are assigned to work with families through the IDEA Part C referral process can be a good support.<sup>21</sup> In addition, the AAP offers a [checklist and tip sheet](#) for parents to follow in navigating the referral process that States can disseminate to local agencies and providers when they engage with families.

## DEVELOP SUPPORTING INFRASTRUCTURE SYSTEMS

States should have integrated or linked data systems to track screenings and referrals throughout the eligibility process.<sup>22</sup> These data systems should allow States to disaggregate by key demographics like age, race, ethnicity, socioeconomic status, or language status, to identify any disparities in who is getting screened and referred within communities and disparities in outcomes of referrals. [Part C Child Find Funnel Chart Tool | DaSy Center](#) can be used by IDEA Part C programs to generate a funnel chart that allows for easy visualization of the data. States should also include information on young children identified as at-risk as part of their tracking system to monitor infants and toddlers before they are referred to IDEA Part C, if they are referred and not found eligible, and after they exit Part C.<sup>23</sup> [Georgia's Child Data System](#) links data across six major early care and education programs, including subsidized child care, home visiting, State preschool, Head Start, preschool special education, and early intervention. This system aligns data from programs and services serving children birth through five and their families and helps the State identify service gaps, target services for underserved children, and support research on program outcomes.

# PUTTING THE STRATEGIES INTO PRACTICE

## HOW CAN STATE PART C ADMINISTRATORS PROMOTE MONITORING, VALID AND STANDARDIZED SCREENING, AND REFERRAL?

### IMPLEMENT WIDESPREAD UNIVERSAL SCREENING

Research has shown that when implemented broadly, universal screening for developmental delays can increase referrals for IDEA Part C among traditionally underserved populations.<sup>24</sup> In addition to referrals from health care providers and other professionals, States can increase families' access to screening and self-referral by making screening measures and tools broadly available online and including links to a State's Part C program to make a referral. States can also provide online step-by-step guides aimed at providers to improve their awareness of the screening and referral process. See the [Delaware Readiness Teams](#) for an example of online resources that have helped families and providers navigate the screening and referral process. Additionally, the [Well Visit Planner](#) is a free tool that operationalizes the AAP's Bright Futures Screening guidelines and provides resources that can be used by parents, providers, and cross-systems partners to promote universal screening.

### INCLUDE SCREENING OF SOCIAL AND EMOTIONAL WELLNESS

Genetics and trauma, among other factors, may contribute to mental health concerns for young children, and these concerns should be addressed as part of the promotion of healthy development. Screening processes should consider infant and toddler social-emotional development and include an assessment of protective factors for the child as well as their family and larger community. The AAP offers a [list](#) of tools that can be used to screen infant and toddler social-emotional development.

## RESOURCE FOR SUPPORT

The [Compendium of Screening Measures for Young Children](#) provides a comprehensive set of 11 screening tools that meet the following quality criteria:

- (a) tool accuracy
- (b) inclusion of family input
- (c) inclusion of the social and emotional domain of development

The tool was developed as part of a Federal task force's [Birth to Five: Watch Me Thrive initiative](#), a coordinated effort to encourage developmental and behavioral screening and support for children, families, and providers.



# PUTTING THE STRATEGIES INTO PRACTICE

## HOW CAN ADMINISTRATORS PROMOTE REFERRALS ACROSS MULTIPLE REFERRAL SOURCES?

### ESTABLISH AND ENFORCE REFERRAL POLICIES

State Part C Administrators can ensure that policies for screening and referral are well-documented and understood by IDEA Part C agencies and partners. Part C administrators should be attuned to regional variations in referral and target public awareness campaigns and trainings to these areas to overcome any information barriers. States can develop web-based tools and communications to support information sharing. For example, Illinois offers a self-paced [Early Intervention Training Program module](#) that walks referral sources through each step of the referral process.

### PROMOTE PRACTICES TO TRACK REFERRALS THROUGH COMPLETION

A State-developed universal referral form can make the process of referring easier for primary referral sources and facilitate data sharing across systems. Providers often indicate that a barrier to referral is not understanding what happens to families after they are referred to Part C. State Part C administrators should work with health care providers and early intervention service providers on how to share data to close the referral loop. The Oregon Pediatric Improvement Partnership offers a [step-by-step guide to the referral process](#), including links to relevant forms and resources, to help families and providers track progress. This support allows initial referrers to track what happened after an infant or toddler was referred, including results of evaluations and services that IDEA Part C will provide so that they can conduct any follow up treatment or coordination of services, as necessary, with the family. This can be a strong incentive for primary referral sources to be more invested in the referral process and reduces the burden on families to bridge communications.

### IMPLEMENT A CENTRALIZED TRACKING SYSTEM

Research shows that centralized referral processes that track infants and toddlers from referral through the eligibility process substantially increase rates of connection to Part C early intervention services.<sup>25</sup> A centralized website where anyone can make a referral and access information about developmental concerns warranting referral, such as [Colorado's Electronic Referral System](#), can promote this process.

### CREATE A LEARNING NETWORK FOR PROVIDERS

Providers often learn best from colleagues, and this can include strategies that have been successful to support developmental monitoring, screening and referral. Part C administrators can bring providers together remotely or in person to provide them with information on IDEA Part C services, including referral and eligibility, give providers the opportunity to share their concerns, and hear how other providers have navigated barriers to support referral to IDEA Part C and connect infants and toddlers with needed services and providers.



# PUTTING THE STRATEGIES INTO PRACTICE

## HOW CAN SCREENING AND REFERRAL CONTRIBUTE TO GREATER EQUITY IN PART C SERVICES?

### PARTNER WITH PARENT TRAINING AND INFORMATION CENTERS (PTIS) AND COMMUNITY PARENT RESOURCE CENTERS (CPRCS)

The PTIs and CPRCs serve as a direct connection for families to resources, and can support referral by helping families understand the referral process and the services offered under IDEA Part C. Because of their involvement with families in various communities and staff's personal experiences engaging with IDEA Part C systems, PTIs and CPRCs can play a key role in helping primary referral sources understand the importance of IDEA Part C services. The Massachusetts PTI has a contract with the IDEA Part C lead agency to support screening and referral efforts. They work with physicians and child care providers on conducting developmental monitoring and screening, the referral process to IDEA Part C, and how to talk with families to help them understand the benefit of beginning the referral process as soon as possible.

### **ENSURE MONITORING, SCREENING AND REFERRAL IS CULTURALLY AND LINGUISTICALLY RESPONSIVE**

States should ensure that monitoring, screening and referral practices are sensitive to cultural and linguistic differences within their communities. As previously stated, families bring their own sets of beliefs and values to the referral process. Communication with parents and families should be tailored to reflect these differences (See more detail in the [Engagement Guide on Outreach and Engagement](#)). Further, valid and reliable screening tools available in multiple languages have been shown to reduce disparities and promote equity in early identification.<sup>26</sup> If there are no valid and reliable screening instrument options available that match a child's culture and language, programs should develop alternative plans for screening children who speak languages other than English. This includes working with interpreters, communicating with families, and interpreting results with caution. The ECLKC has [resources](#) that can help programs make decisions on screening children who speak languages other than English.

### **PROMOTE FLEXIBLE APPROACHES TO SCREENING AND REFERRAL**

State Part C administrators should work with families, health care providers, early childhood providers, and other primary referral sources to help them identify how to address barriers to completing the screening and referral process. For instance, promoting more widespread use of [telehealth for screening by primary referral sources](#) may address some of the distance and access issues experienced by families who have work conflicts, have long distances to travel, or want to involve multiple family members in the process.





# ENDNOTES

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