Recommendations on Developmental Screening Follow-up Practices and Policies for Federal, State, and Community Level Stakeholders

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Introduction

The foundation for future health, academic success, and career success is related to early experiences. When development is delayed or disrupted, developmental supports are needed as soon as possible regardless of the cause of the disruption. The adults in a child's life and the early childhood system of services must respond early and swiftly when there are developmental concerns.

Developmental and behavioral screening are strategies that can identify young children who need additional support early. According to the 2018-2019 National Survey of Children's Health data, only 32.47 percent of parents with children ages 9 through 35 months reported using a parent-completed screening tool in the past year.[i] Although some states have made progress in expanding screening rates in recent years, it is essential that improvements continue to be made so that all young children receive timely recommended developmental screening. It is equally important that children who are found through screening to have a developmental concern that could benefit from follow-up, monitoring, and/or intervention can receive the supports they need. Unfortunately, service capacity is often not sufficient to meet demand. Many of these children and families do not meet the eligibility criteria for programs such as Part C early intervention that could address these concerns directly. Programs that could provide developmental support and monitoring, such as home visiting programs, Early Head Start, and childcare, often have limited capacity, specific eligibility criteria, or are difficult to access. Many Early Childhood Comprehensive Systems (ECCS) grantee states have identified a need for further guidance and recommendations on follow-up practices when infants and young children demonstrate continued developmental concerns on screening results and do not qualify for Part C or other services.

What is Part C?

The Program for Infants and Toddlers with Disabilities (Part C of IDEA) provides intervention services to infants and young children birth to three years. Congress established this program in 1986 and revised the findings in 2019 to:

- Enhance the development of infants and toddlers with disabilities, to minimize their potential for developmental delay, and to recognize the significant brain development that occurs during a child's first 3 years of life.
- Reduce the educational costs to our society, including our Nation's schools, by minimizing the need for special education and related services after infants and toddlers with disabilities reach school age.
- Maximize the potential for individuals with disabilities to live independently in society.
- Enhance the capacity of families to meet the special needs of their infants and toddlers with disabilities.
- Enhance the capacity of state and local agencies and service providers to identify, evaluate, and meet the needs of all children, particularly minority, low-income, inner city, and rural children, and infants and toddlers in foster care.

Eligibility for Part C is determined by each state's definition of developmental delay and how the state defines presumptive eligibility (such as identifying diagnosed physical or mental conditions that qualify an infant/toddler, for example Down Syndrome).[ii] Over the years and with limited funding, states have narrowed their eligibility criteria for Part C early intervention. Part C federal regulations allow states to serve infants and toddlers at-risk of having a developmental delay; however, only six states include at-risk within their eligibility guidelines.[iii]

What is ECCS CoIIN?

The Early Childhood Comprehensive Systems Collaborative Improvement and Innovation Network (ECCS CoIIN) is a five-year effort (August 1, 2016 through July 31, 2021) to improve early childhood developmental screening and referral services in 28 communities across 12 states. The goal of this program is to increase age-appropriate developmental skills among three-year-old children and reduce developmental disparities. The ECCS grantees are working to demonstrate a 25 percent increase in age-appropriate skills among participating communities' three-year-old children. The logic model for the ECCS grantees includes the following goals to:

- Create a Common Agenda/Shared Vision & Strategies
- Develop Shared Data Systems
- Promote Aligned & Mutually Reinforcing Activities
- Provide Backbone Support & Mechanisms for Continuous Communication between State & Community
- Disseminate EC Development/Systems Information
- Integrate Early Developmental Promotion, Screening, Referral, Linkage, & Developmental Processes Across and Within Sectors and Communities
- Build Care Coordination Capacity
- Support Continuous Learning & Improvement Efforts
- Develop & Maintain Partnerships & Networks
- Family Leadership
- Build Public Will
- Advance Policies & Mobilize Funding to Sustain System Improvements

The National Institute for Children's Health Quality (NICHQ) is the lead agency supporting state teams in the ECCS CoIIN effort. Funding is from the Health Resources and Services Administration Maternal and Child Health Bureau. ZERO TO THREE (ZTT) is one of the partners working with NICHQ.

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There have always been children with mental health challenges that have not received the early support needed. As the Centers for Disease Control and Prevention (CDC) expands the *Learn the Signs, Act Early* campaign to focus more on screening for mental health concerns in young children, additional children may be identified with developmental concerns. With additional children identified with social and emotional concerns, the challenge of where and how to address follow-up services may be exacerbated. Historically, children with developmental concerns in the behavioral health and social-emotional domain have proven the most difficult to address through our existing early childhood and early intervention infrastructure.

This paper explores challenges of the early childhood service delivery system and offers recommendations for state policy and system change to ensure children and families receive help when developmental delays are present. We also include examples of bright spots in specific states. Although a central focus is on the Part C early intervention system, other services are also discussed in recognition that Part C does not operate in a vacuum but is part of a continuum of supports and services. Special attention is paid to how infants and toddlers who are not found eligible for Part C early intervention can be supported. Successful state and community strategies are shared throughout. While the COVID-19 pandemic is not a focus of this paper, we include brief discussion of it and the broader federal funding context in recognition that states' policy options are often constrained by insufficient federal funding.

What Does the Data Tell Us?

National research suggests that the prevalence of developmental delays and disabilities among children under age three who can benefit from early intervention services is between 13 percent and 20 percent.[iv] Data shows that only a fraction of these children are receiving supports through Part C early intervention. In 2018, Part C served 3.5 percent of the United States population of children under the age of three.[iii, iv] These statistics are even more alarming when looking at the experiences of children of color and children from families with low incomes,[vi] who research has shown, do not have equitable access to early intervention services and often experience disruptions in the pathway from screening to referral to evaluation and enrollment.[vi,viii, ix] This inequity limits the ability of Part C early intervention programs to reduce disparities in developmental outcomes.

Federal Policy Context

Over the last decade, several briefs discussing how to improve Part C services and developmental screening practices have been written, including Making Hope a Reality: Early Intervention for Infants and Toddlers with Disabilities, (ZTT, 2009); Early Intervention: A Critical Support for Infants, Toddlers, and Families, (ZTT and CLASP, 2017); and Early Childhood Developmental Screening and Title V: Building Better Systems, (AMCHP and NICHQ, 2017). Similar challenges and recommendations are identified in each brief, yet few changes have been made. Given what we know about the importance of early brain development and how early development sets the stage for future success, the time to make bold changes is now.

The Part C early intervention system is underfunded and has been for decades. Mandates such as the Child Abuse Prevention and Treatment Act (CAPTA) have been issued without additional resources to support early childhood systems. This resource scarcity has shaped the landscape of Part C early intervention, and the broader system of supports for young children and families of which Part C is a part. It is time to fully fund the Part C early intervention system so it can adequately address the needs of children with developmental delays, disabilities, and at-risk conditions.

This need has never been clearer than it is in the current moment, as the COVID-19 pandemic is spotlighting unprecedented threats to child development across the nation. The pandemic has resulted in both health and economic fragility and has vividly illuminated the structural and systemic racism that continues to harm families of color. Young children may be forgotten in the sphere of family and economic stressors. Predictable routines have been disrupted with childcare closures. The family routine is unsettled with parents working at home while caring for their young children. Many families face economic uncertainty with no work and limited or no income. The mental health of parents and children is vulnerable.

In the wake of COVID-19, young children and parents will have greater needs for services and concrete support. At the same time, the impacts on state and federal budgets may make it difficult to meet these growing needs. Although it may be challenging to consider expanding investments in early childhood services, the need for support is only going to increase. Federal funding for Part C services needs to be dramatically increased to enable state systems to respond to the demand for services and need for innovation. This paper includes several recommendations for states and communities to consider. However, we recognize that states and communities cannot implement many of these recommendations without action being taken at the federal level.

For more information regarding federal policy recommendations, see ZTT's recent publications *Building for the Future: Strong Policies for Babies and Families After COVID-19*, *Building Back Better for Babies and Toddlers: ZERO TO THREE's Transition Plan*, and *Recovery Begins with Babies and Families: An Agenda for the Administration and the 117th Congress*.

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Identifying Strategies to Access Services After a Developmental Screening

To better understand challenges and promising strategies states and communities are experiencing in accessing services following a developmental screening, ZTT conducted a series of interviews and small group discussions with representatives from states and national organizations in August and September 2020. As this issue is central to the work of the ECCS grantees, most participants were drawn from that project, though additional stakeholders active in this area were also included. A full list of individuals interviewed is in the acknowledgements section at the end of the paper.

We identified four core themes that are critical in implementing effective developmental screening, referral, and follow-up through these discussions. Challenges, successful strategies, and recommendations for policy and system change shared during interviews and focus groups are summarized for each theme below.

Four Themes Critical to Screening, Referral and Follow-Up

- Increase Access to a Continuum of Early Childhood and Family Supports and Services
- Improve Early Childhood System Infrastructure Including Developmental Screening Practices
- Strengthen Professional Capacity
- Ensure Family Engagement and Parent Voice

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North Carolina's Care Coordination for Children (CC4C)

North Carolina's Care Coordination for Children (CC4C) is a free and voluntary program that helps families find and use community services. CC4C care coordinators serve children zero to five years of age who have or are at risk for developmental delay or disability, long-term illness, social emotional problems, or toxic stress. Common referrals include:

- Infants who are discharged from the newborn intensive care unit.
- Children with special health care needs.
- Children in this age group who enter foster care.
- Children and families who have had a positive screen in their primary care practices (including developmental and behavioral health screening, autism screening, and maternal depression screening).
- Children who meet CC4C toxic stress criteria, including domestic/family violence, caregiver unable to meet infant's health and safety needs/neglect, parent(s) with a history of parental rights termination, active alcohol and/or substance abuse by caregiver, unstable housing, unsafe living environment, parent/guardian suffering from depression or other mental health condition, or homelessness or living in a shelter.
- Children and families referred for the Plan of Safe Care, which is for infants diagnosed with NAS (neonatal abstinence syndrome) and hospital nurseries are required to notify the Division of Social Services (DSS) and DSS refers to CC4C.

The program uses a two-generational model that utilizes Life Course Progression to assess risks and strengths and set goals with families. CC4C staff are primarily registered nurses or social workers employed by local health departments. They regularly communicate and collaborate with the child's medical home and help connect families to services such as quality childcare, family support, mental health resources, and GED resources. CC4C is funded through a Medicaid Managed Care program called Care Management for At-Risk Children (CMARC) and Title V funds. County-based services receive a per-member, per-month Medicaid rate based on the zero-to-five population of the county, and Title V funds are used to provide CC4C for eligible children not covered by Medicaid.

CC4C, which has a high rate of acceptance from families referred (approximately 8 percent of children statewide who are between ages zero and five are referred), provides care management for 75 percent of these referrals. Of the children and families referred for Plan of Safe Care, virtually 100 percent accept the service. These numbers reflect the success of CC4C in engaging families who stand to benefit from its diverse services.

Increase Access to a Continuum of Early Childhood and Family Supports and Services

Young children need access to a continuum of services and supports that promotes their healthy development. This is especially true for children who are found through developmental screening to have, or be at risk of developing, a developmental delay or disability. Research has shown that early intervention can improve children's cognitive and social skills, lead to higher achievement and greater independence, and promote family competence and well-being. Unfortunately, most states and communities do not have sufficiently robust systems to serve all children and families who could benefit. Challenges that contribute to this problem include inadequate funding for early childhood services, restrictive eligibility criteria for Part C early intervention, and lack of a safety net for children who do not qualify for Part C but need support.

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CHALLENGES AND SUCCESSFUL STRATEGIES

Comprehensive system of early childhood and family support services

Young children and families need a comprehensive system of early childhood and family support services at different levels of intensity, inclusive of high-quality childcare, home visiting, programs to address material needs and economic security, Part C early intervention, developmentally appropriate mental health services, and primary care. Developmental screening works best when it is embedded in a system that holistically supports families and also includes screening and supports for social determinants of health, family protective and risk factors, maternal depression, and family's basic needs. Administering a screening is not the end goal, but part of the continuum in promoting the well-being of children by helping families access services. A comprehensive system of early childhood and family support services needs to be funded at a level that ensures everyone who needs services can receive them. Even if Part C is bolstered, it will not be the answer for all children. Ensuring an array of supports and services and adequately funding an early childhood system that can meet the needs of all babies, young children, and their families is essential.

Summary of the many strategies ECCS awardees are using to embed developmental screening in the early childhood service delivery systems.

- Building parental understanding of development through community events, targeted education, and use of technology, including developmental focused apps.
- Promoting utilization of validated parent driven screening tools such as the ASQ.
- Expanding types and numbers of providers who can administer a developmental screen through cross-sector professional development.
- Offering developmental materials and encouragement of screening in more community locations such as WIC offices and childcare centers.
- Adapting developmental screening materials to be more culturally relevant.
- Creating shared data systems to collect and report developmental screening outcomes.
- Supporting workflows of referral and follow up to community providers if concerns are identified.
- Utilizing data about developmental screening outcomes for future planning.
- Influencing policy and reimbursement to better support developmental screening practice.

Eligibility criteria for Part C early intervention services

Historically, Part C was perceived to be the safety net for children identified with developmental concerns. Overall, more infants and toddlers with significant delays are being served by Part C than ever before. However, the dollar amount appropriated per child of federal and state funding has not kept pace, therefore states' eligibility criteria have become more restrictive over time in order to serve those with the most significant delays. In interviews with stakeholders, there was a theme that Part C has also become more narrowly focused on a few specialized services, such as occupational, physical, and speech therapy, and is challenged with considering broader developmental areas such as social and emotional health. Interviewees also reported varying eligibility among states also confounds the safety net notion; and provided the example that even within states, there are often significant differences in how teams evaluate a child and determine eligibility, resulting in a family receiving Part C services in one part of the state and another similarly presenting child determined ineligible in another part of the state.

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Although serving children at-risk of having a developmental delay is permitted by Part C federal regulations, only six states allow for children "at-risk" for developmental delays to receive Part C services.[x] Referring providers have become frustrated when children and families are clearly struggling but are determined not eligible. Children who are not eligible for Part C may not have access to other early childhood service systems or may not be able to get the individualized supports and services they need through other early childhood programs. Funding should be increased at the state and federal levels and eligibility broadened and made more uniform across states.

KEY POLICY AND SYSTEMS CHANGE RECOMMENDATIONS:

- States expand eligibility of Part C to include at-risk infants and toddlers and ensure eligibility determination is a consistent process among teams across the state.
- States fully fund (through local, state, and federal funding) an early childhood system with a sufficient continuum of services and supports.
- Communities identify a safety net for children with developmental concerns who do not meet eligibility for Part C and create services and supports missing within the local landscape.

Connecticut Offers a Comprehensive Continuum of Services

Using a variety of federal, state, and local funding sources, Connecticut has developed a comprehensive continuum of services for young children. Key features include:

Help Me Grow 2-1-1 Child Development Infoline (CDI)

- Help Me Grow is available for any family who has a question about their child's development or behavior. Through CDI, HMG offers access to the Ages and Stages Questionnaire (ASQ) monitoring, and monitors development for children under three – including those not eligible for Part C – and connects families to community-based programs and services to address their needs. CDI is also participating in the Sparkler Initiative to provide needed supports if concerns are identified through that app.
- CDI offers services for children not eligible for Connecticut's Part C early intervention program. Services provided include:
  - Free developmental screening program from birth to age 5, via online or mailed questionnaire (ASQ). Information about child development and behavior;
  - Community-based programs and services such as referrals to home visiting, childcare, parenting programs, and parent education supports; and
  - Networking and training opportunities for community providers.

Home Visiting

The Office of Early Childhood uses a combination of state funds and federal Maternal, Infant, and Early Childhood Home Visiting (MIECHV) funding, to facilitate "The Connecticut Home Visiting System," which includes six home visiting models (Nurse Family Partnership, Parents As Teachers, Early Head Start, Family Check-up, and Minding the Baby). All programs adhere to the benchmarks of the federal MIECHV program. All use an app called Sparkler to conduct developmental and social-emotional screening using ASQs.

Family Resource Centers

These centers are located in public schools and offer comprehensive family support and child development services. They are modeled off the "Schools of the 21st Century" concept developed by Dr. Edward Zigler of Yale University.

Connecticut Birth to Three

State legislation passed in 2013 designated the Connecticut Birth to Three (the state's Part C early intervention system) as the provider of mental health services to any child eligible for early intervention services. In addition, any child under the age of three who has a screening that indicates a behavioral health concern will be referred to the Birth to Three System. The evaluation team will include a mental health clinician. If the child is found not eligible for Birth to Three but mental health concerns are identified the program, with parental permission, must refer the child to a licensed mental health care provider for evaluation and treatment, as noted per Connecticut Public Act 13-178.[xi] If permission for referral is refused, the program should record this in the child's record and leave information on mental health resources with the parent. Funding for Part C services includes an EPSDT Early Intervention Service approved by CMS in 2017 as part of the state Medicaid Plan Amendment. A fee-for-service model promotes joint visits from multiple professionals at the same time based on need and pays for EI treatment services from a long list of qualified providers.

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Improve Early Childhood System Infrastructure Including Developmental Screening Practices

Developmental screening works best when there are clear protocols for how referral and follow-up should be conducted, and when systems are in place to support execution. State and local guidance is needed to support coordinated communication and reimbursement. Administering a screen is an initial step in ensuring children are receiving the supports they need to foster healthy development. Breakdowns occur when early childhood professionals who are conducting screens are not clear on their role in the screening process or do not know where they should refer families if developmental concerns are present. The system is flawed when families are referred for services and do not receive them because they are ineligible, or programs are full. Barriers to communication and coordination among service providers can also impede service delivery. It is essential that states and communities work together to address these barriers.

CHALLENGES AND SUCCESSFUL STRATEGIES

State and local infrastructures

At the state level, it is helpful to have clear and concise policies on processes to access services to facilitate coordination and collaboration at both the state and local level. The state needs to define reimbursement procedures and strengthen the infrastructure necessary to support robust developmental/behavioral screening and referral. Examples may include establishing incentives for providers who conduct screenings and improving technology platforms that facilitate collection and sharing of data. Information about procedures and infrastructure supports must be clearly communicated to all screening providers and partners (such as pediatricians, childcare providers, home visitors, or other early childhood professionals).

Screening, referral, and follow-up protocols

Professionals working with young children need to know the agreed upon process for screening, from administering the tool, to referral, to assessment, to service delivery. Providers must have a clear understanding of who administers the developmental screen and why screening is important. When this process is vague or unclear, some children are screened multiple times in different settings while other children are missed. A key aspect of coordination is a clear, predictable, and agreed upon communication process among parents and professionals. Creating a feedback loop helps ensure the screening professional is aware of the results of the assessment. The subsequent services received reinforces the message that screening alone is not enough. It is also important that reimbursement policies are clear and specify who receives payment and the specific service.

HealthySteps Provides a Developmental Specialist - TARRANT COUNTY, TEXAS

In Tarrant County, Texas, My Health My Resources oversees both Part C and the HealthySteps program across eight sites. HealthySteps, a program of ZERO TO THREE, is a primary care based enhanced pediatric model. HealthySteps includes a child development specialist (known as the HealthySteps Specialist) on the care team. Their expertise and frequent contact with young children in the primary care setting often enable them to better understand whether children may be eligible for Part C, and act as a pre-screening resource. With lean budgets, this can help reduce the expense of evaluating children who are ultimately not eligible. HealthySteps Specialists can also work more closely with children and families who need additional support but may not be eligible by providing support during and between well-child visits and brief behavioral health consults. They can also re-screen children with increased frequency to monitor their progress over time in a way that most pediatric practices lack the time to do systematically.

HealthySteps Specialists can also reduce the need for some infants and toddlers from needing early intervention services due to the services they provide to families and children beginning at birth. HealthySteps and similar programs can assist in operationalizing the federal Child Find requirement. Enhanced primary care programs and Part C can work well together to enable a more coordinated effort for providers to work across the continuum toward a shared goal.

As a population-level health prevention program, in part, the strength of HealthySteps is to help young children and families particularly around toxic stress and adverse childhood experiences (ACEs), which can lead to behavioral or social emotional challenges. Many HealthySteps Specialists report that these are often the children who do not receive Part C services because there is a less clear fit or eligibility requirements for non-physical developmental challenges or delays.

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Coordination to support families in receiving services

When further assessment is needed, a process must be in place to assure families receive help. Ideally, when a concern is identified, a warm hand-off is done to connect families with an appropriate service rather than simply providing the parent a telephone number. Some communities have had success pairing families with community health workers or health navigators who help families obtain the services they have been referred to. For example, these professionals may partner with the family to access a Part C evaluation or connect the family to other state and community supports such as food and housing assistance, high quality childcare, or home visiting. Centralized intake and referral systems have also shown success in families receiving necessary support.

Data-driven decision-making

Data plays an important role in assuring screenings and follow-up services are delivered in a timely manner. Shared data systems among community providers assist with communication and help prevent the duplication of services. Shared data can also help providers know what specific services are available and if there are openings for new families. Help Me Grow provides a strong data component, shares information about available services, and connects families to what is available. Medicaid data could help communities and states better understand who is being screened and analyze the results within the population of children served by Medicaid. Unfortunately, data is often not collected with the level of detail needed for such analyses. For example, if health providers receive a bundled payment for well-child visits, they may not report whether they conducted any screenings as part of the visit. In other cases, providers may note that a screening was conducted, but not provide detail on the type of screen so there is no way to know if it was for development, social emotional health, autism or ACEs. In order to make the best decision for a child and family, providers need to know – with parent consent – whether a child has been screened, the results of the screening, referrals made, services accessed, and programs available to provide support.

KEY POLICY AND SYSTEM CHANGE RECOMMENDATIONS:

- States develop written protocols on screening practices delineating who is responsible for screening, what to do after a screen is conducted, how to refer for further assessment, and how to access needed supports.
- States require and fund the provision of family navigators, peer support specialists, or community health workers to partner with parents in navigating the service delivery system. Consider embedding these professionals in a central intake and referral system.
- States develop and use a data system to track screenings, referrals, and subsequent services received.
- States create infrastructure to support professionals in integrating and sustaining developmental screening workflows and reinforce in professional development opportunities.

Connecticut Children's Medical Center

Connecticut Children's Office for Community Child Health

Commonly referred to as the Office, this program leads the way in addressing the social, environmental, and behavioral factors that keep children from reaching their full potential. One effort of the Office includes:

Promoting Healthy Development

Research shows that as much as 90 percent of child health outcomes are due to factors outside clinical care and the Office is committed to addressing those factors to help all children reach their full potential. The Office programs (such as The Help Me Grow National Center) work to build partnerships across all of the sectors that are known to impact child development and well-being, such as early learning, housing, home visiting, transportation, food and nutrition, and family support services. Such partnerships make it easier for families to access both the medical care and non-medical community supports they need to thrive.

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Strengthen Professional Capacity

Investing in workforce development has long been a common theme raised by national and state representatives. All early childhood professionals, regardless of the program they work in, need to have a broad understanding of early childhood development across domains, including social and emotional health. It is also important for all professionals to develop strong and effective communication skills for use with different audiences, such as parents and community partners. Creating aligned competencies and cross-sector professional development can be effective strategies to ensure all professionals working with young children have the same foundational knowledge. For those involved in screening, referral, and follow-up, it is also important that they have the training needed to understand and execute their role in the process.

CHALLENGES AND SUCCESSFUL STRATEGIES

Competence in child development

Professionals working with young children and families in various disciplines (such as childcare, home visiting, health, mental health, child welfare, etc.), would benefit from having a broader understanding of child development and the role that each domain plays in supporting children's growth. Pre-service training is often discipline-specific and narrow in scope. It is in the best interest of children and families for professionals to engage in professional development opportunities with each other so people from different disciplines share foundational knowledge and have opportunities to better understand the language and perspectives of other sectors. It is also important for professionals working with young children to understand wider family challenges that can have an impact on child development, such as social determinants of health, and where to find community services and resources to address them.

Knowledge of social-emotional development

Young children's social and emotional health supports development in other essential areas including physical development and health, cognitive skills, language and literacy, social skills, and children's approach to learning. Yet too often early childhood professionals receive little pre- or in-service education focused on children's social and emotional health. All professionals need a basic understanding of infant and early childhood mental health (IECMH), which is defined as the developing capacity of a child from birth to 5-years-old to form close and secure adult and peer relationships; experience, manage, and express a full range of emotions; and explore the environment and learn, all in the context of family, community, and culture. It is not necessary for everyone working with young children to be an IECMH clinician, but it is important for all professionals to understand social and emotional development, how they can support it, and how to recognize if there is a need for concern.

Proficiency in administering and interpreting a developmental screen

Early childhood professionals across service delivery areas need to know how to administer developmental and behavioral health screens, how to interpret the results, and when and where to refer families for support. They also need to understand the screening protocols put in place by their community and state related to approved standardized screening tools, referral feedback loops, collection and sharing of data, billing and reimbursement policies, and system navigation. A one-time training is not sufficient; ongoing support is needed to ensure professionals are able to appropriately change their internal practices to ensure they are properly administering screening tools and taking the appropriate next steps. Sustainable workflow changes need to be made to ease burden and enhance ease of tracking and monitoring developmental screening. Strategies such as utilizing a system that completes scoring automatically and generates referrals for areas of concerns will allow more consistent and comprehensive screening across providers.

KEY POLICY AND SYSTEM CHANGE RECOMMENDATIONS:

- States require professionals are competent in all developmental domains including social and emotional well-being and provide cross-sector training for all professionals working with young children and families.
- States provide training and support of a diverse workforce of family leaders/navigators.
- States require and pay (such as through Medicaid plans and private insurance) for the administration of a valid and reliable social emotional screen in addition to a broad developmental screen.
- States provide professional development and coaching to providers (health, early care and education, home visiting) administering developmental screens and referral to support practice transformation.

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Pennsylvania Strengthens Early Childhood System Infrastructure and Professional Capacity

Pennsylvania has taken the following steps to strengthen the infrastructure that supports developmental screening, referral, and follow-up:

Workforce development

Regional Early Learning Resource Centers provide coaching to early care and learning programs around developmental screening and supporting children with disabilities. For over 10 years the Office of Child Development and Early Learning (OCDEL) has supported an initiative providing both the ASQ 3™ and ASQ:SE2™ to any early learning program who participates in an approved training on these tools. Additionally, Part C early intervention (EI) staff can help programs with planning, curriculum, and modifications to include children with behavioral health concerns. The Commonwealth also provides cross-sector training to staff from OCDEL, EI advisors and technical assistance consultants, IECMH consultants, and ECE coaches.

Connecting children to services

Pennsylvania has broader eligibility criteria for Part C early intervention than many states. Children are eligible if they demonstrate a 25 percent delay in at least one area or by informed clinical opinion (i.e., a specialist determines that there is a delay even if not indicated on the evaluation). Recognizing that children with social and emotional concerns may not show a delay, but could benefit from support, the Commonwealth developed tools and training to help EI evaluators and providers determine when a child should be found eligible. If a child is determined not eligible for Part C, the EI service coordinator creates a transition plan with the family and works with them for up to 15 days to obtain needed services, such as medical assistance, behavioral health services, childcare, housing, and food assistance. The Commonwealth also has processes in place to ensure smooth transitions from Part C to Part B 619 services, including a shared data system and an option for families to stay in the Part C system for an extra year.

In addition, Pennsylvania provides at-risk tracking for children not eligible for early intervention services. Developmental screening and tracking services include a process to regularly assess the development of a child who is at risk for developing a delay. An infant or toddler may be eligible for tracking services through the EI program if they are at risk for a developmental delay based on one of the following categories: cared for in a hospital's neonatal intensive care unit, prenatal substance exposure, including alcohol exposure, referred by a county children and youth agency, low birth weight, exposed to lead, or experiencing homelessness.

Additional funding

Pennsylvania includes EI services in its Medicaid State Plan. Medicaid pays for service coordination (which includes evaluation, services, and referral to any other community resources) for children who are eligible for EI.

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Encourage Family Engagement and Parent Voice

Strong relationships are central to effectively working with families. It is important that all early childhood professionals have strong communication and relationship building skills. The ability to engage in a flexible manner and respond in the moment is helpful. Parents must also be included at policy tables to inform an effective and responsive early childhood service delivery system. They must be part of the development of programs and delivery processes to help create systems that truly support families.

CHALLENGES AND SUCCESSFUL STRATEGIES

Family engagement skills

Family engagement skills are key to developing trusting relationships with families. Ideally, parents should feel comfort and safety with the professionals supporting their child and family. Just as it is best to let a child take the lead in play, it is helpful to let the parent take the lead in expressing hopes, dreams, and concerns about their child. Rather than listening to a parent's priorities and needs, professionals across disciplines often tell parents what they need without taking the time to listen. Strengthening family engagement skills should be part of pre- and in-service preparation for all early childhood professionals. Professionals should receive guidance in talking with parents about screening results, particularly how to talk about developmental concerns that screening identifies, and the options families have for addressing them.

Family voice in policy discussions

Parents' voices are critical in developing policies that are in the best interest of young children and families. Parents who reflect the racial and ethnic background of the communities served need a seat at decision-making tables to ensure solid practices are developed that will work for families. Parents touch all the systems in their child's life, and therefore have a front row seat in seeing the inequities and barriers to accessing services. The conversation changes for the better when parents are involved with the development of policies and practices. Parent representatives should be involved in developing policy and practice recommendations at the state and local levels from the start and be reimbursed for their time and perspectives.

KEY POLICY AND SYSTEM CHANGE RECOMMENDATIONS:

- States require professional development for early childhood professionals focused on building their skills to authentically communicate with and engage families.
- Federal, state, and community decision-makers adapt committee and workgroup practices and schedules to ensure parents can meaningfully participate and reimburse parents for their time and expertise.
- Federal, state, and community decision-makers partner with parent representatives to determine policy and practice changes.

Conclusion

Science has illustrated that babies cannot wait. There is a need to administer developmental screens, including social and emotional screens, to ensure babies and young children are progressing and reaching the expected milestones in all domains of development. When a concern is identified, further assessment is warranted. If there is a delay or risk of delay, supports need to be put in place to help rectify the delay regardless of criteria, cut off scores, and income. The Part C service delivery system is governed by rules, finance restrictions, and eligibility criteria which impact access to services. Early intervention has an opportunity to further ameliorate delays and save money and hardship in future years by applying a prevention lens on the rules, finance restrictions, and eligibility criteria that guide programming.

It is necessary for communities to come together and grapple with how to best support their youngest citizens. Part C and other early childhood and family support programs need to fund and support a robust and responsive system of care to bolster all children and families. There must be buy-in for developmental screening and the follow up referral process to community supports and services. The early childhood system of care is based on relationships, coordinated care, and the knowledge that babies cannot wait.

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Recommendations on Developmental Screening Follow-up Practices and Policies for Federal, State, and Community Level Stakeholders

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