STATEWIDE ADVOCACY AGENDA TO IMPROVE PART C EARLY INTERVENTION SERVICES FOR PENNSYLVANIA









TABLE OF CONTENTS

Acknowledgements3
I. Introduction and Approach4
Scope of the Project4
Participants in Development of Advocacy Agenda5
II. Overview of the Early Intervention Program 6
Core Principles of Part C Early Intervention in Pennsylvania6
III. Priority Recommendations At a Glance11
IV. Priority Recommendations12
 Serving all children who can benefit from Part C EI through outreach, referral, enrollment12
Issues and Solutions related to Outreach, Referral, and Evaluation (ORE)15

to make a difference (Q)
Issues and Solutions related to Quality (Q)19
3. Achieving equitable access in Part C El21
Issues and Solutions related to Equity (EQ)23
4. Addressing mental health needs of infants and toddlers in Part C El24
Issues and Solutions related to Mental Health26
5. Partnering with Medicaid to improve Part C El27
Issues and Solutions related to Mental Health29

Acknowledgements

Pennsylvania Association for the Education of Young Children (PennAEYC) is an affiliate of the National Association for the Education of Young Children (NAEYC) and is a dynamic membership organization of early childhood care and education professionals. Our mission is to be an effective voice for high-quality early childhood care and education. We do this through policy development, advocacy and professional development and supports for early childhood professionals. PennAEYC's vision is that all Pennsylvania families will have access to high-quality, affordable early childhood care and education opportunities for their children provided by a profession that is valued, well compensated and supported.

Pennsylvania Partnerships for Children (PPC) is a strong, effective, and trusted voice to improve the health, education, and well-being of children and youth in the commonwealth. Throughout our nearly 30-year history,

our public policy victories have helped countless children learn, thrive, and succeed. With a vision to ensure every child living in Pennsylvania can thrive and reach their full potential, PPC is committed to considering policy solutions that also improve maternal health and advance racial equity.

Focusing on five core policy areas – child welfare, early childhood education, home visiting, K-12 education, and maternal and child health – PPC is statewide, independent, nonpartisan, and nonprofit.

The William Penn Foundation funded this project. The William Penn Foundation, founded in 1945 by Otto



and Phoebe Haas, is dedicated to improving the quality of life in the Greater Philadelphia region through efforts that increase educational opportunities for children from low-income families, ensure a sustainable environment, foster creativity that enhances civic life, and advance philanthropy in the Philadelphia region. Since its inception, the Foundation has made nearly 10,000 grants totaling over \$1.6 billion. The opinions expressed in this report are those of the author(s) and do not necessarily reflect the views of the William Penn Foundation.

Many people worked together to support the development of this policy action agenda for Early Intervention Part C, including many people from throughout Pennsylvania who contributed their insights to this report; our consultants Harriet Dichter, Kay Johnson, and Elisabeth Burak; and staff from PPC and PennAEYC including Justin Beyler, Jen DeBell, Kim Early, Kelly Hoffman, Kari King, Maggie Livelsberger, Becky Ludwick, Keevan Merryman, and Rachael Miller.

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I. Introduction and Approach

Pennsylvania Partnerships for Children (PPC) and Pennsylvania Association for the Education of Young Children (PennAEYC), with support from three early childhood consultants, came together to assess and inform development of an action agenda for Pennsylvania's Part C Early Intervention (EI) system. An in-depth assessment, including participation from over 150 individuals, led to the statewide agenda outlined in this report.

Scope of the Project

The focus of this advocacy agenda is Part C of the Early Intervention (EI) system, which serves infants and toddlers and their families. Early Intervention in Pennsylvania also provides services to preschool age children. While there are many similarities between these programs, and they have similar goals, the programs have different federal requirements. A similar project is needed to address and further support the preschool age component of Early Intervention.

This statewide legislative and administration action agenda was developed with input and information from multiple sources: a resource scan of national data and reports, consideration of the structure and approach to Part C in Pennsylvania, and many individuals. We sought individual and organizational input using small group discussions and two full participant meetings. This multi-step engagement process enabled all interested participants to play a key role in shaping the action plan, providing feedback at each stage of the process from mid-2021 through mid-2022.

Initially we met with 150 individuals who had many different roles in Early Intervention. Small group discussions were organized by role so that individuals

Figure 1. Key Elements Informing Advocacy Agenda

- Resource scan of national data and reports
- Small group discussions with 150 individuals, organized by role, to share EI experiences, identify strengths, challenges and opportunities for improvement
- 3. Two large group meetings with go plus individuals synthesizing information on strengths, challenges and opportunities for improvement, and mutual agreement on recommendations for the action plan
- 4. Multiple meetings with the
 Pennsylvania Office of Child
 Development and Early Learning
 (OCDEL) to gather and confirm
 information and to review strengths,
 challenges and opportunities for
 improvement

with shared roles met together. Discussions were led by the consultants, using a semi-structured discussion guide. Participants shared their experience with the Part C Early Intervention (EI) program, based on their views of strengths, challenges, and opportunities for improvement.

While participants brought forth issues on their own, the protocol allowed for probing in the following areas:

- · Child Find and referrals
- Eligibility and enrollment processes, including Individualized Family Service Plan (IFSP)
- Range of conditions and diagnoses



- Equitable access (e.g., by geography, race/ ethnicity, income, and disability/health status)
- Provider availability (e.g., range of services, provider types)
- Transition from Part C to IDEA Preschool Special Education or other services
- Systems collaboration and partnerships

In addition, we met periodically with the Deputy Secretary, Pennsylvania Office of Child Development and Early Learning (OCDEL), and her staff to gather information, ensure the accuracy of information, and to review and discuss what we were hearing from the many individuals who participated in the small group discussions.

Following the resource review and the small group discussions, the team synthesized all of the information on the Part C EI system to identify key strengths, key issues for improvements, and recommendations. A summary document was provided to all participants. Two interactive

Participants in Development of Advocacy Agenda





- Early care and education providers
- Early Intervention providers and service coordinators
- **Families**
- Managed care organization (MCO) staff
- Pediatric health care providers
- State administration staff
- State legislative staff

community meetings allowed all participants clear opportunities in the process to learn from each other

and to review and refine emerging priorities.

II. Overview of the Early Intervention Program

The federal Early Intervention Program for Infants and Toddlers with Disabilities—now authorized under Part C of the Individuals with Disabilities Education Act (IDEA)—was established in 1986. The Part C program, administered by states, seeks to ensure early intervention (EI) services to children with disabilities as early as birth through age 2 (to the third birthday) to: 1) enhance the development of infants and toddlers with disabilities. 2) reduce educational costs by minimizing the need for special education through early intervention, 3) minimize the likelihood of institutionalization by and maximizing opportunities to live at home and in the community, and 4) enhance the capacity of families to meet their child's needs. Overall, it aims to improve outcomes that are critical to health, optimal development, educational success, and lifelong wellbeing.

The Part C EI services are structured to identify and meet the needs of infants and toddlers in five developmental areas: physical development, cognitive development, communication development, social or emotional development, and adaptive development. In every state, the Part C EI requires and helps to support development and implementation of a statewide, comprehensive, coordinated, and multidisciplinary interagency system to make early intervention services available for all infants and toddlers with disabilities and their families.

The program is designed to help families with children who have developmental delays or a high probability of having a developmental delay. Under federal Part C El rules, an infant or toddler with a disability is defined as an individual under 3 years of age who needs El services because the individual is experiencing a developmental delay in one or more of the five areas of development or has a diagnosed physical or mental condition that has a high probability of resulting in developmental delay (IDEA, Section 632(5)(A)). Within this broad federal definition, states have the authority to establish eligibility criteria such as the conditions or the level of developmental delay needed for Part C eligibility (IDEA, Section

635(a)(1)). For example, 37 states include hearing impairments, 32 states include Down syndrome, 32 states include low birthweight, 25 states include autism spectrum disorders, and 22 states include preterm birth on a list of conditions or criteria for Part C EI eligibility. (Barger et al., 2021, https://journals.lww.com/iycjournal/Abstract/2019/10000/State_Variability_in_Diagnosed_Conditions_for_IDEA.2.aspx)

Core Principles of Part C Early Intervention in Pennsylvania



- Provide services and supports to infants and toddlers with disabilities and their families to help the child grow and develop—to be familycentered.
- Embed services and supports within daily routines and learning opportunities in natural home and community settings.
- Build on existing supports and services within the family, community, and early education resources.
- Provide coordinated, flexible services and supports through personnel working collaborative with the family and each other.
- Provide services and supports focused on the transition between and among programs.

Adapted from "A Family's Introduction to Early Intervention in Pennsylvania" and "Pennsylvania's Approach to the Delivery of Early Intervention Services."

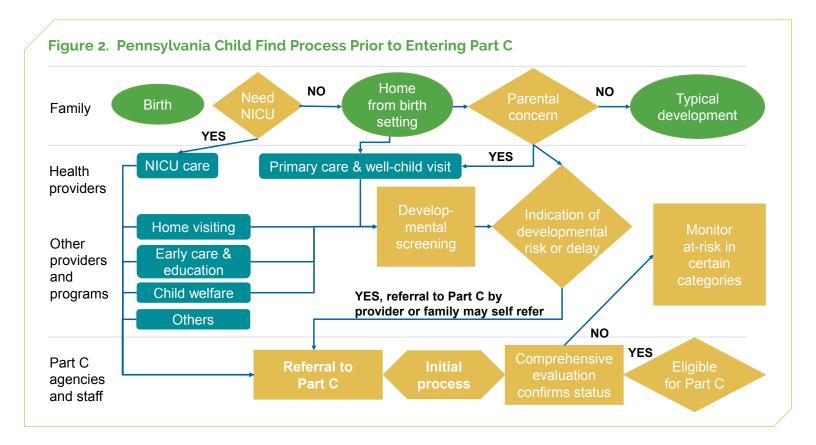
In addition, at a state's discretion, infants or toddlers with a disability may also include: a) individuals younger than 3 years of age who would be at risk of having substantial developmental delay if they

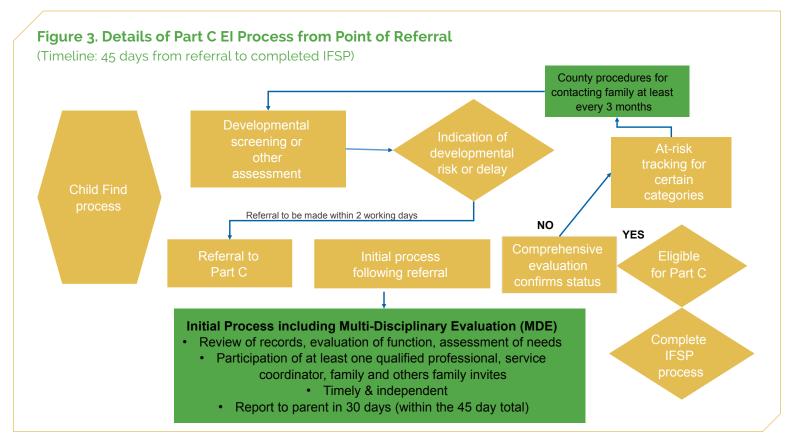
did not receive early intervention services; and b) individuals 3 years of age and older with disabilities who are eligible to receive preschool services under IDEA, Part B, Section 619, until such individuals are eligible to enter kindergarten or an earlier timeframe. The Part B Section 619 program is focused on preschool-aged children from 3 through 5 years.

In Pennsylvania, the program is jointly overseen by the Department of Education (Part B) and the Department of Human Services (Part C), with direct administration by the Office of Child Development and Early Learning (OCDEL).

Pennsylvania counties have responsibilities that affect virtually all operational aspects of the Part C EI program (PA Chapter 4226). These responsibilities include administrative and linkage structures for: a Child Find system, eligibility determinations and at-risk category tracking, fiscal administration, contracts with providers, monitoring and data reporting, and so forth.

Each states' Part C El program is required to have a Child Find system, which must include referral procedures (IDEA Part C Sections 303.302 and 303.303). These procedures must detail general referral approaches, specific procedures for use by primary referral sources, as well as those tailored for specific infants and toddlers who are the subject of a substantiated case of child abuse or neglect or are identified as directly affected by illegal substance abuse or withdrawal symptoms resulting from prenatal drug exposure. Primary referral sources include birth hospitals/neonatal intensive care units (NICUs), pediatric primary care providers, early care and education providers, other health or social service agencies, and those who serve vulnerable families in homeless shelters and domestic violence agencies. In addition, families may self-refer to Part C for screening and evaluation to determine eligibility. Figure 2 shows the elements of the Pennsylvania Child Find process prior to entering the Part C El program.

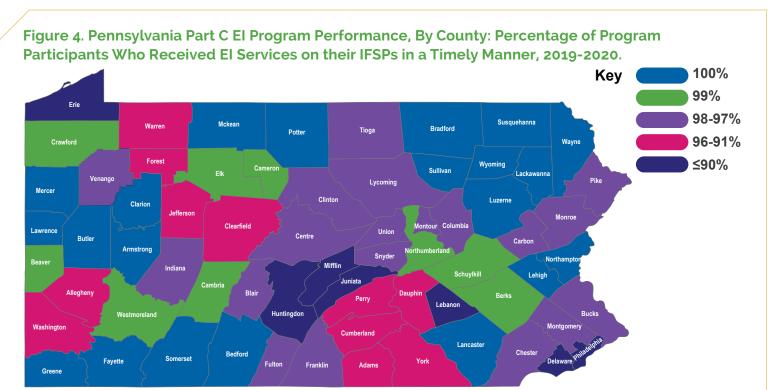




The Part C EI process from referral to eligibility determination must adhere to specific procedures, structures and timelines. As shown in Figure 3, the two key elements, as required by federal law are an initial process and a multi-disciplinary evaluation (MDE). In Pennsylvania, these steps are closely intertwined. If the MDE confirms the child is eligible, the process step to create an Individualized Family Service Plan (IFSP) begins. Part C El service coordinators and other professionals develop the IFSP with the family, identifying the goals and outcomes important to the child and family, what services they already have, what services and supports they need, and the specific services to be delivered and financed under Part C EI. Early intervention services are required to begin no later than 14 calendar days from the date of completion (and signing) of the IFSP unless a later date has been specified.

Part C EI programs can provide information on how children develop, therapies to help a child to move his or her body or communicate, services to support social-emotional development, information designed to help a family enhance their child's growing and learning, and ideas for how an early care and education provider can help the child in a child care or other setting. Service types include, but are not limited to, service coordination, family training, speech-language services, occupational and physical therapies, audiology, vision services, psychological and social work services, nutrition services, assessment and evaluation services, and nursing support and health services necessary to enable a child to benefit from other El interventions.

Generally, Pennsylvania ranks highly on key federal performance measures for the Part C EI program. Families report that Part C EI services help them to communicate with their child (97.0%), help their child learn (99.5%), and know their rights in the process (96.4%). Data from a related survey of Pennsylvania families shows that 99% of families felt they were part of the IFSP decision-making process and 96% agreed that EI helped them address concerns during the transition process. These high levels of family satisfaction with the Part C EI program are a strength



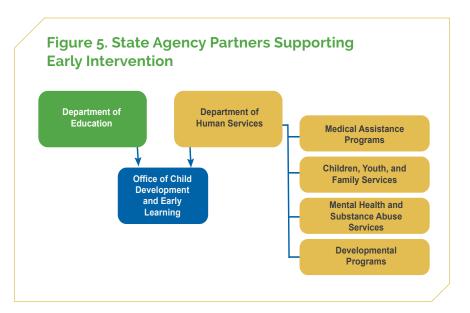
Source: BEISFS. Pennsylvania Early Intervention Annual Performance Report: Data on the FY 2019 Infant Toddler and Preschool Early Intervention Programs

in Pennsylvania and reflect the commitment of the state's program to partnering with families.

In 2019-2020, 93.9% of Pennsylvania families using the program reported their children received services specified on their IFSP on time. As shown in Figure 4, however, performance in delivering timely services varies by county.

Federal appropriations for Part C El are limited and fall short of covering the full cost of the program in every state. Funding for the Part C El program in Pennsylvania includes: a) federal Part C funds, state El funds, and county matching funds (10% of federal dollar allocation to county) via the county-level Part C program, and b) Medicaid fee-for-service payments to El providers from both regular Medicaid financing and the Infant, Toddler, and Family waiver. By law, federal Part C funds are required to be the last funding source used (i.e., payer of last resort).

Successfully serving infants and toddlers with or at risk for developmental delay requires partnership and collaboration across state agencies and among child serving systems. The Pennsylvania Office of Child Development and Early Learning (OCDEL), part of both the Department of Education and the Department of Human Services, oversees Part C EI (See Figure 5).

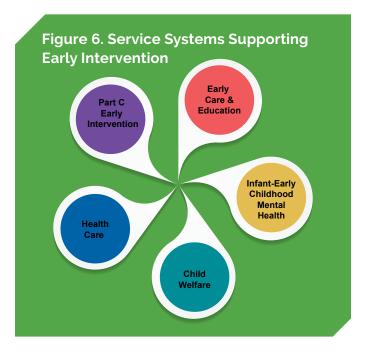


II. Overview of the Early Intervention Program (continued)



Within the Department of Human Services, several other offices are key partners to Part C El's success. The Office of Medical Assistance oversees Medicaid, a key source of financing for Part C El services. The Office of Children, Youth, and Families has responsibility under federal law to engage in a process that ensures referral of children under age 3 who have a substantiated case of child abuse and neglect. The Office of Mental Health and Substance Abuse Services plays a role in structuring mental health services for infants and toddlers, as well as for their caregivers. The Office of Developmental Programs administers Medicaid waiver programs for home and community-based services and makes other policy and practice decisions that affect the lives of young children with disabilities.

Multiple child and family service systems must work in concert to assure that each infant and toddler's health, developmental, mental health, safety, and other needs are met. In particular, successful delivery of Part C EI services to address the risks and needs of infants and toddlers requires clear communication, interaction and linkages among service systems driven by each child and family's needs as identified in the IFSP. As shown in Figure 6, at least five key child service systems contribute to the success of the Part C El program. The Part C El service providers themselves play a dominant and central role. Health care providers—including birthing hospitals, neonatal intensive care units and pediatric primary care providers—are central points of broad contact in screening and referring children to Part C EI. Since many infants and toddlers spend time in



early care and education settings such as child care, close partnership with EI providers is also essential for success in promoting optimal development. For some young children with mental health conditions or risks that fall both inside and outside of Part C EI service structures, collaboration between Part C EI and infant-early childhood mental health providers may be necessary.

Last but not least, child welfare systems and providers must be linked to and work in collaboration with EI providers since infants and toddlers experiencing child abuse and neglect are at high risk for developmental delays. Federal law requires processes for referral to Part C for children with substantiated child abuse and neglect.

III. Priority Recommendations At a Glance

Serving all children who can benefit from Part C EI through outreach, referral, enrollment

- ORE 1. Strengthen support for education, outreach, and participation
- ORE 2. Design a clear and effective pathway from maternal depression screening
- ORE 3. Improve linkages between pediatric primary care providers and El
- ORE 4. Change the child abuse and neglect referrals process

2. Ensuring Part C El services offer **quality** needed to make a difference

- Q1. Provide program funding to counties to support workforce quality
- Q2. Assure that all EI providers can plan and provide services together as a team
- Q3. Address inconsistencies and inequities in EI processes and performance at the county level
- Q4. Create an EI consultation role for child care programs
- Q5. Consistently use Informed Clinical Opinion
- Q6. Fully implement the coaching model

3. Achieving equitable access in Part C El

- EQ 1. Increase outreach, referral, enrollment, and support for families of color and those who speak a language other than English
- EQ2. Partner with higher education to recruit and train individuals from historically underserved communities and immigrant communities to join the EI workforce
- EQ3. Introduce Early Intervention as a career opportunity to participating families, the child care workforce, and during high school

- EQ4. Provide ongoing antibias, cultural responsiveness, and equity workforce development
- EQ5. Increase county-level data by race/ethnicity

4. Addressing **mental health** needs of infants and toddlers in Part C EI

- MH1. Ensure social-emotional-mental-behavioral health (SEMBH) is integrated into El evaluation and Family Service Plans
- MH2. Ensure county agencies responsible for Part C and MH/DD are creating a clear pathway to early childhood mental health services, whether through Part C EI or other mental health services
- MH3. Increase opportunities for service coordinators and EI providers to obtain the infant-early childhood mental health (IECMH) credential
- MH4. Include IECMH consultants as part of EI evaluation and service delivery

Partnering with **Medicaid** to improve Part C EI

- MA1. Study the adequacy of rates and take action to address identified problems, providing for routine rate review and adjustments
- MA2. Use Medicaid data to address variations in utilization and spending for EI services
- MA3. Leverage Medicaid MCO contracts and quality/performance initiatives to stimulate pediatric primary care developmental screening and referrals
- MA4. Leverage Medicaid MCO contracts and quality/performance initiatives to increase maternal depression screening and referrals
- MA5. Use increased federal funding for Medicaid home and community-based services (HCBS) to enlarge support for infants and toddlers with disabilities

IV. Priority Recommendations

Our recommendations are found across five priority areas:

- Serving all children who can benefit from Part C EI through outreach, referral, enrollment
- 2. Ensuring Part C El services offer **quality** needed to make a difference
- 3. Achieving equitable access in Part C El
- 4. Addressing **mental health** needs of infants and toddlers in Part C EI
- Partnering with **Medicaid** to improve Part C EI

Each of these five areas contains four to six priority actions that build upon strengths of the Part C EI and address areas for improvement.

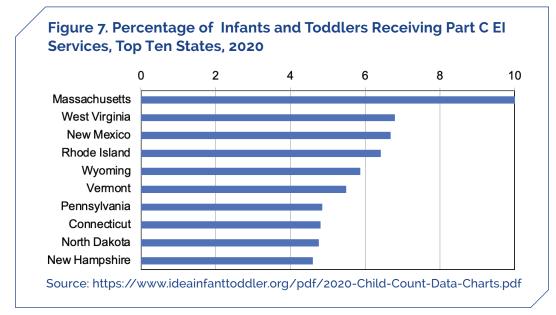
The recommendations for action to improve Pennsylvania's Part C Early Intervention program build upon the many areas of strengths that put the program in a strong place to continue to develop. These strengths include the breadth of eligibility categories, and, as a result, Pennsylvania is among the top ten states in terms of the percentage of infants and toddlers enrolled in Part C. (See Figure 7.) With 4.8 percent of the population of infants and toddlers receiving services

at any time in Pennsylvania, the state performs well above the national average of 2.8 percent in recent years. Notably, Pennsylvania is the only large state in the top ten highly ranked performers by population enrolled in Part C, with more than 42,000 infants and toddlers receiving services annually.

Other strengths relate to using partnerships, implementing best practices, and leveraging all available financing. Our state has a long tradition of family engagement and leadership as a foundational element of Part C Early Intervention, including partnerships with families and support for children in their natural environment, whether that is their home or their child care program. Another strength is the implementation of an evidence-based coaching model for delivery of EI services, reflecting national prioritization of this approach. This action builds new skills and supports into a system already using standardized evaluation tools and other best practices in delivery of El services. While not all states do so, Pennsylvania seeks to maximize available public resources by tapping various federal and state funding streams, including Medicaid, to finance the early intervention services to which children are entitled.

Serving all children who can benefit from Part C EI through outreach, referral, enrollment

The Pennsylvania Part C EI program aims to meet federal requirements for outreach, referral, and enrollment, including the Child Find, multidisciplinary evaluation (MDE), and eligibility determination processes. The goal is to identify, evaluate, and enroll



the families of all eligible infants and toddlers with developmental disabilities and conditions likely to lead to developmental disabilities. Participants engaged in the program assessment discussed an array of challenges and opportunities on this topic. In particular, they emphasized the importance of having consistent and equitable processes. As a result of gaps in Part C EI outreach, referral and enrollment processes. some infants and toddlers who could benefit from services are not getting them. Providers and parents reported challenges for some families in navigating the process, particularly families with cultural and linguistic barriers who might benefit from more peer support. Participants also offered suggestions for improvement, particularly related to the connections from screening to referral to evaluation.

Effective EI linkages to other systems such as early care and education, child welfare, and health are also important factors for outreach, referral, enrollment, and quality. Systems and process issues related to screening and referrals were identified for children in the child welfare system, those whose mothers are depressed, and those without a routine source of primary care (e.g. pediatrician or family practitioner).

What does research say about this topic?

Effective outreach, referral and enrollment:

National data indicate that only a small fraction of infants and toddlers participate in Part C EI and that states' eligibility, outreach, and enrollment processes have an impact on participation levels. Multiple studies of factors influencing family engagement in Part C EI have found that parents' perceptions of their children's development, practical barriers such as time off work or transportation, and the ease of connecting with program providers are key. Support for families in navigating and understanding the process from referral to further screening and assessment is critical. Without support through the Part C process, studies show between 20-35 percent of children referred do not receive an evaluation. These actions are particularly important for infants and toddlers who do not have a diagnosed condition

associated with developmental delays. (Decker et al., https://doi.org/10.1007/s10995-020-03067-2; Atkins et al., 2020 https://doi.org/10.1007/s10995-019-02830-4; McManus et al., 2020 https://doi.org/10.1186/s12887-020-1965-x; Barger et al., 2019 10.1097/iyc.000000000000000151; Barger et al., 2018 https://doi.org/10.1177/0271121416678664; Hackworth et al., 2018 https://doi.org/10.1016/j.uchworth, 2018 https://doi.org/10.1016/j.uchworth, 2016 https://doi.org/10.1016/j.uchworth doi. 2017.01.009; Barger et al., 2016 https://doi.org/10.1177/0271121416678664; Rosenberg et al., 2014 https://doi.org/10.1542/peds.2012-1662)

Peer navigators and community outreach: Families, particularly those from culturally and linguistically diverse backgrounds, often face barriers in navigating Part C and the health care system without support, including a lack of understanding of the referral process. Family members with lived experience are increasingly being recruited and deployed to serve as peer navigators. Navigator roles typically include education, support, and assistance in accessing resources. Peer support has been shown to reduce stress and increase El participation when infants have conditions that can cause developmental delays and disabilities. In addition, grandparents and other frontline community workers can provide support and facilitate connections for families. (Fratantoni et al., 2022 https://doi.org/10.1038/s41372-022-01341-5; Pandy et al., 2019 https://doi.org/10.1080/ 08952841.2018.1444940; Reid et al., 2019 https://doi. org/10.11124/JBISRIR-2017-003958; Luke et al., 2018 https://doi.org/10.1093/pch/pxx176; Palfrey et al., 2019; Belcher et al., https://doi.org/10.1002/ddrr.137; Gooding et al., 2011 https://doi.org/10.1053/j. semperi.2010.10.004; Jimenez et al., 2011 https://doi. org/10.1016/j.acap.2012.08.006; Silow-Carroll, 2009)

Maternal depression screening: Maternal depression can have serious consequences for both mother and child. Maternal depression affects parenting and is associated with social-emotional behavior problems, developmental delays, impaired cognitive development, and language skills among the

depressed mothers' infants and children. Nearly 50 percent of mothers of subpopulations of children with conditions that can lead to developmental delay (e.g., preterm birth, autism spectrum disorders, and cerebral palsy) experience depression. While high prevalence is alarming, effective treatment for maternal depression, including parent-child dyadic treatment to improve child development, is well established. Professional organizations and governmental guidelines, including the American Academy of Pediatrics, recommend postpartum depression screening for all mothers during the first year of a child's life as part of the child's regular check-ups. Clear, effective screening and referral processes related to a positive maternal depression screening are critical to minimizing its impact. Because the risk of developmental issues for infants and toddlers is high when mothers are depressed, referrals to Part C for assessment of developmental status are warranted. (Harmon et al., 2019 https://doi.org/10.1007/s10802-020-00740-6; Slomian et al., 2019 https://doi. org/10.1177/1745506519844044; Meany, 2018 https:// doi.org/10.1176/appi.ajp.2018.17091031; Trussell et al., 2018 https://doi.org/10.1177/0009922818769450; Feinberg et al., 2012 https://doi.org/10.1007/s10995-010-0715-3; Ertel et al., 2011 https://doi.org/10.1089/ iwh.2010.2657: Knitzer et al. 2008)

Linkages with pediatric primary care/medical

home: Primary health care providers are among the most frequent source of referrals for Part C EI program services because of the more frequent check-ups, called well-child visits, that occur in the first two years of a child's life. The effectiveness and number of referrals to Part C EI for those beyond the newborn period depends heavily on the practices of pediatric primary care providers (including pediatricians, family physicians, and others). The American Academy of Pediatrics and other expert bodies recommend developmental screening and surveillance for infants and toddlers at specified intervals and a response to screen results that warrant further action. National surveys of pediatric

primary care providers report an expectation to be informed about the results of the referral and ongoing El services for their patients, in effect to have timely and ongoing flow of information between the medical home and the Part C program. (Sanders et al., 2021 https://doi.org/10.1097/
DBP.00000000000001004; US Department of Education, 2011; Adams et al., 2013 https://doi.org/10.1542/peds.2013-2305; Ross et al., 2018 https://doi.org/10.1007/s10995-018-2540-z; Jimenez et al., 2014 https://doi.org/10.1016/j.acap.2014.01.007)

Referrals from Child Welfare to Part C EI: Since 2003, federal law has required states to have policies and procedures in place for the referral to Part C El of all children younger than 3 with substantiated cases of abuse or neglect. (42 USC Section 5106(a)) States have the discretion as to whether to refer every such infant and toddler for early intervention services, or to first employ a screening process to determine whether a referral is needed. The available data suggest that only a small proportion of these vulnerable infants and toddlers are connected to and ultimately enrolled in the Part C EI system. Lack of familiarity with or training for conducting screening among child welfare agency personnel are a barrier to screening and linkage with Part C El. Studies of states' implementation show that this requires increased El system capacity, strong interagency linkages, and strategies to engage families entering the child welfare system. The effectiveness of screening and evaluation processes makes a difference. (Shannon, 2020 https://doi.org/10.1080/ 15548732.2020.1727395; Administration for Children and Families, Children's Bureau, 2019; Administration for Children and Families, CAPTA 2018; Casanueva et al., 2008 https://doi.org/10.1177/1077559508318397; Derrington & Lippitt, 2008 https://doi. org/10.1177/0271121408320350; Mott & Dunst, 2006 https://doi.org/10.1177/105381510602900102; Robinson & Rosenberg, 2004 https://doi. org/10.1177/105381510402600404)

Issues and Solutions related to Outreach, Referral, and Evaluation (ORE)

Please note that the first recommendation found in priority 3, achieving equitable access in Part C EI, is relevant to the overall recommendations in this section. The recommendation is to increase outreach, referral, enrollment, and support for families of color and those who speak a language other than English; additional information is found in the equity section.

Issue Gaps in the Part C EI processes for outreach, referral and enrollment result in infants and toddlers not

getting the services from which they could benefit. Providers and parents reported challenges for

some families in navigating the process.

Solution Strengthen support for education, outreach, and participation of families in EI through a) introduction

of EI navigators and family ambassadors to support education, outreach and participation, and b) education and outreach with home visiting, community health, grandparents, frontline workers addressing homelessness, those working with immigrant and refugee families, to build awareness of

the benefits of EI and facilitate linkages to EI.

Type Administrative

Additional funding may be needed for new initiatives

ORE 2. Design a clear and effective pathway from maternal depression screening

Issue Children with depressed mothers are at higher risk for developmental delays. Gaps in processes lead

to missed opportunities for treatment and early intervention.

Solution Design a clear and effective pathway from maternal depression screening to EI referral and services

for the child, including education for EI professionals and support and referrals for the birthing parent

to be connected to services.

Type Administrative and legislative

Additional funding may be needed for implementation

ORE 3. Improve linkages between pediatric primary care providers and EI

Issue Pediatric primary care providers are not consistently informed about results of their referrals to Part C

El or what is included in Individualized Family Service Plans among those infants and toddlers found

eligible.

Solution Improve the linkages between pediatric primary care providers and the Part C EI system (e.g., close

the referral loop so that pediatric primary care providers know what happened after referral; share information about the child's IFSP; build knowledge of pediatric associations, MCOs and others about understanding of EI and how it works, encourage pediatric providers to participate in local

interagency coordinating councils).

Type Administrative

Minimal additional funding needed

ORE 4. Change the child abuse and neglect referral process

Issue Infants and toddlers with substantiated cases of child abuse and neglect are not always getting

effective screening, referrals to Part C EI, and/or multi-disciplinary evaluation (MDE), despite risks to

them.

Solution Change the child abuse and neglect referral process. Currently, requirement to do developmental

screening for all infants and toddlers with substantiated cases of child abuse and neglect may be by referral to Part C, done by child welfare, or otherwise. Instead, require county children and youth agencies to refer all infants and toddlers with substantiated cases of child abuse and neglect for screening and MDE, including all domains of development. Those not found eligible based on MDE

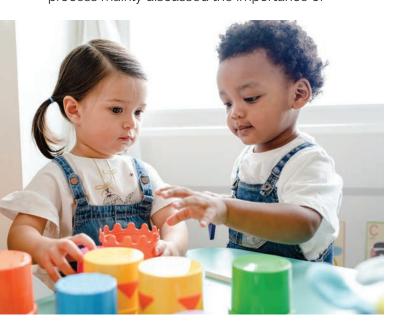
would move to the at-risk tracking group in Pennsylvania.

Type Administrative and legislative

Changes may be required in policy and funding

Ensuring Part C El services offer quality needed to make a difference (Q)

Assuring quality for Part C EI programs begins with the foundation of a quality framework and system design already employed in Pennsylvania. Such foundational features include broad eligibility criteria, clear regulations, support for workforce development, consistent implementation, and adequate financing. Participants in this review process mainly discussed the importance of



workforce training and sustainability, particularly as the state implements the evidence-based coaching model, which requires all EI providers and service coordinators to learn new ways of working with families. In addition, Part C EI providers are not compensated for the professional development time that is essential to quality service delivery. Since many EI professionals work as contractors to local agencies, ensuring adequate support for professional development, while essential, is more complex. The ability of multiple EI providers in the team to deliver services together, at one time with the family, was also raised as a key concern.

Many infants and toddlers in Part C EI also spend time in early care and education settings. Both EI and child care providers discussed the challenge of cross-system collaboration to maximize the effectiveness of the services they deliver to infants and toddlers. While Part C EI services are being delivered in child care and other early education settings, detailed roles/responsibilities and support structures would lead to more effective partnerships.

The Part C El program is grounded in communities, with counties playing a critical role in its administration. Yet review participants identified challenges stemming from significant inconsistencies

in processes between counties that contribute to inequitable access for families depending on where they live. Consistency and quality in the eligibility determination process, which includes the multidisciplinary evaluation of a child's developmental and health status, was a particular topic of interest. Parents, providers, and service coordinators all emphasized the importance of having equitable and consistent methods across all areas of the state. In particular, providers and families reported that use of Informed Clinical Opinion in the process was not consistently available across counties in Pennsylvania.

What does research say about this topic?

Quality workforce for EI: Quality in EI services depends to a large extent on the availability of and access to well-trained providers, as well as having sufficient hours of service, make a difference in short- and long-term outcomes. For most participating families, services are delivered by multiple EI professionals and guided by a service coordinator. The effectiveness of services depends

on a coordinated approach and a partnership with families. (US Department of Education, 2021; Guralnick & Bruder, 2019; Kasprzak et al., 2019 https://doi.org/10.1177/0271121419831766; Woodman et al., 2018 https://doi.org/10.1016/j. ecresq.2018.01.007; Dunst, 2015 https://doi.org/10.1097/IYC.00000000000042; McManus et al., 2014 https://doi.org/10.1007/s10995-013-1332-8; Early Childhood Technical Assistance Center Part C of IDEA)

Service Teams in Part C: Federal law assumes an IFSP team for each child/family served and Part C guidance promotes multi-disciplinary collaboration. The IFSP team meets initially and annually to develop an appropriate plan for services to be delivered under Part C EI. This team includes: the service coordinator, those who conducted evaluations and assessments, those who will provide the EI services to this child, and the parents (and other family members or advocates if requested by parents). (IDEA Part C Section 303.343) In addition to the initial and annual meetings, the quality of Part



C EI services can be improved when the service coordinator, providers, and family meet periodically throughout the year to coordinate delivery of services identified on the IFSP. (Bricker et al., 2020 https://doi.org/10.1177/0271121419890683; Coufal & Woods, 2018 https://doi.org/10.1016/j.pcl.2017.08.027; Hunt et al., 2004 https://doi.org/10.1177/02711214040240030101)

Child care as a service setting: Many infants and toddlers spend a portion of their day in child care programs, and children in Part C EI have a right to appropriate services in these natural environments. At the same time, studies suggest that EI and child care providers have challenges in communication and alignment of approaches. Even adapting the physical location of services (e.g., in a separate room, in a busy classroom) may be challenging. Having more structured support for child care settings can help to bridge gaps and improve services for children. Development of cross-sector supports, technical assistance, and professional development is recommended in federal guidance. (Chödrön et al., 2021 https://doi.org/10.1007/s10995-020-03097-w; Sheppard & Moran, 2021 https://doi. org/10.1007/s10643-021-01225-x; Weglarz-Ward et al., 2019 https://doi.org/10.1177/1053815119886110; Weglarz-Ward & Santos, 2018 https://journals.lww. com/iycjournal/Abstract/2018/04000/Parent_ and_Professional_Perceptions_of_Inclusion.4.aspx; US Department of Health and Human Services and Department of Education, 2015)

Informed Clinical Opinion: The term Informed Clinical Opinion appears in the regulatory requirements for implementation of Part C EI and the state must ensure that it may be used as an independent basis to establish a child's eligibility. (IDEA. Section 303.321(a)(3)(ii)) Informed Clinical Opinion is used by EI professionals in the evaluation process, making use of information on aspects of development that are more difficult to measure. In other words, when a standardized test or measurement tool won't be effective in measuring



a child's condition, professionals can observe and assess developmental delays. Documentation of Informed Clinical Opinion is part of the process. (ECTA Center, 2012; Shackelford, 2002)

Coaching: El programs recognize the importance of engaging parents in their child's development. Coaching is an evidence-based strategy that can be used by early interventionists to engage families as decision makers and participants in their children's intervention. Research evidence strongly supports "coaching" parents on how to integrate therapies into routines and daily activities, rather than relying only on an hour or two per week of intervention with an EI professional. Studies also suggest that coaching can empower families and can be effective with culturally and linguistically diverse families. To get optimal outcomes for children and families, however, El providers need additional training and supervision as they implement coaching methods. (Pellecchia et al., 2020; https://pilotfeasibilitystudies. biomedcentral.com/articles/10.1186/s40814-020-00568-3; Romano & Schnurr, 2020 https://doi. org/10.1177/0271121419899163; Ward et al., 2019 https://doi.org/10.1080/09638288.2019.1581846 ; Steward & Applequist, 2019 https://doi.org/10.10 80/02568543.2019.1577777; Kemp & Tunbull, 2014 https://doi.org/10.1097/IYC.00000000000018; Rush et al., 2003 https://doi.org/10.1097/00001163-200301000-00005)

L<mark>8</mark> June 2022

Issues and Solutions related to Quality (Q)

We note that there are four recommendations found in priority 3, achieving equitable access in Part C EI, that are equally relevant to the overall recommendations in this section. These recommendations follow; additional details are found in the Equity section.

EQ2. Partner with higher education to recruit and train individuals from historically underserved communities and immigrant communities to join the EI workforce

EQ3. Introduce Early Intervention as a career opportunity to participating families, the child care workforce, and during high school

EQ4. Provide ongoing anti-bias, cultural responsiveness, and equity workforce development

EQ5. Increase county-level data by race/ethnicity



Q1. Provide program funding to counties to support workforce quality

Issue The professionals who provide Part C EI services to families are not compensated for the professional

development time that is essential to quality service delivery; funding is not available for induction and mentorship of EI professionals who are new to Part C service delivery. Many EI professionals work as contractors, which exacerbates the issue. Dedicating program funding to counties specifically for

quality workforce professional development will help address this issue.

Solution Provide program funding to counties, over and above fee-for-service billing, to pay for the time of EI

providers to participate in professional development, provide funds to providers to support quality of

contractors, and implement statewide induction/mentorship for all new EI providers.

Type Legislative

Additional financial resources required

Q2. Assure that all EI providers can plan and provide services together as a team

Issue Children and their families may be best served when the EI professionals can provide services at the

same time. Likewise, periodic team meetings are needed that bring together all the EI professionals, the service coordinator, and the family. However, teaming in service delivery and regular team

meetings are not routinely part of El.

Solution Assure that all EI providers can plan and provide services together as a team, at one time, for a

child/family, when appropriate. At a minimum, provide program funding for periodic team meetings that include providers, service coordinator, and family. Adopt a clear mechanism that has allowable

billable hours for the EI provider team to meet together to case conference with the family.

Type Administrative and legislative

Additional financial resources required

Q3. Address inconsistencies and inequities in El processes and performance at the county level

Issue The Part C El program is grounded in communities, with counties playing a critical role for

administration. However, parents, providers and others note significant inconsistencies and inequities in how EI is administered at the local level, which can result in inequitable service delivery to children

and their families. County performance in serving children is not consistent.

Solution Address inconsistencies and inequities in El processes and performance at the county level, based on

public/private review of work flow and expected processes (e.g., provider continuity and availability, diagnoses for eligibility) and performance data, including family satisfaction, race/ethnicity, and

disability/developmental status.

Type Administrative

Minimal additional funding needed

Q4. Create an El consultation role for child care programs

Issue Many infants and toddlers spend time in child care programs, making these settings one location where

El services may be delivered. Both El and child care providers report the challenge of learning and sharing information during the course of a clinical visit in a busy child care setting. The system is lacking El consultants who could help inform, coach, and improve the supportive role of child care providers.

Solution Create and provide funding for an El consultation role for child care programs (parallel to the ECMH

consultant role for child care) to provide coaching and assist with developing teacher skills relative to

the early intervention needs of children in their care.

Type Administrative and legislative

Additional financial resources required

Q5. Consistently use Informed Clinical Opinion

Issue Informed Clinical Opinion is required to be part of Part C EI assessment processes when needed.

Providers and families report that Informed Clinical Opinion is not consistently available across the

state as part of assessments that determine eligibility for Part C El.

Solution Review county and provider level inconsistencies and clarify the guidance for Part C related to the

use of Informed Clinical Opinion statewide.

Type Administrative

Minimal additional funding needed

Q6. Fully implement the coaching model

Issue Pennsylvania has made a strong commitment to use the evidence-based coaching model to

deliver Part C EI services. Continued effort is needed, however, to ensure a well-trained and fairly

compensated workforce to deliver the coaching model with effectiveness and quality across the state.

Solution Continue implementation and funding for statewide use of the coaching model, including adequate

rates to bill for visits and program funding to develop workforce skills.

Type Administrative

Minimal new funding required

Achieving equitable access in Part C El

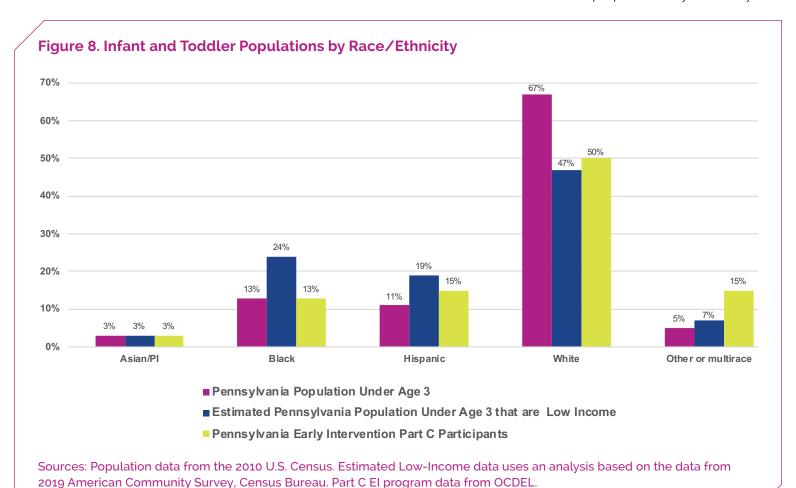
June 2022

Participants in this review process described concerns about achieving and assuring equity in the Part C EI Program across geographic, race/ethnicity, disability/health status, and income. IDEA, at its core, is a civil rights law designed to guarantee access to services and supports for traditionally underserved children with disabilities (who were long left out of education and other services). Thus, Part C EI and its system, agency and community partners bear a shared responsibility to help all children to realize their full potential, beginning with equitable and effective outreach processes and continuing through service delivery. The providers, parents, and others who participated in this system review emphasized

the importance of increasing the racial and ethnic diversity of the EI workforce, which has traditionally been predominantly white. Increasing opportunities for underrepresented people to have a career path in EI professional roles was raised as an important strategy, along with ongoing training to reduce bias and increase cultural responsiveness among EI providers. Collecting and reporting program participation and performance data by race/ethnicity is essential to monitoring equity in access to Part C EI services.

Additional state and county level Part C EI program data disaggregated by race/ethnicity can help Pennsylvania monitor performance and target barriers. Pennsylvania has a diverse population of young children as detailed in Figure 8. While Pennsylvania's low-income Black and Hispanic infants and toddlers are disproportionately less likely

21



IV. Priority Recommendations (continued)

to be served by the Part C EI program, these groups are more likely to experience risk factors associated with developmental delays: preterm birth, inadequate food or housing, exposure to lead, or parents with mental health concerns. Research indicates that language barriers, lack of access to primary care, and EI program structure can lead to unequal participation patterns.

What does research say about this topic?

Assuring equity in Part C EI: National survey data indicate that Black and Hispanic young children are less likely than their peers to receive Part C EI services. The disparities in receipt of EI services are greater among those who have a developmental delay alone, without a diagnosed medical condition. National data also show disparities in diagnoses of developmental disabilities, with children

of color more likely to be identified later and with behavioral rather than medical conditions. Cultural and linguistic barriers are a major factor in disparate participation rates. Gaps in access to primary care and to developmental screening are also drivers of inequities. In addition, studies show that having program staff and providers who are of the same race/ethnicity increases family participation and reduces the changes of provider bias. (Sheldrick et al., 2022 https://doi.org/10.1001/ jamapediatrics.2021.5380; Slomski, 2022 https://doi. org/10.1001/jama.2022.2187; Boone-Blanchard et al., 2021 https://doi.org/10.1177/0271121421992470; Scott & Desrosier, 2020; Rivero et al., 2019 https:// doi.org/10.3389/fpsyg.2019.00872; Ross et al., 2018 https://doi.org/10.1007/s10995-018-2540-z; Feinberg et al., 2011 https://doi.org/10.1097/ DBP.obo13e3182142fbd)



<mark>222</mark> June 2022

Issues and Solutions related to Equity (EQ)

Note that the equity recommendations are also integral to other recommendations. The first recommendation is connected to the outreach recommendations and the remainder are relevant to the quality recommendations.

EQ1. Increase outreach, referral, enrollment, and support for families of color and those who speak a language other than English

Issue Low income Black and Hispanic families are underrepresented in participation in Part C El. For

culturally and linguistically diverse families, more tailored outreach and support through the Part C EI

evaluation and enrollment process is needed.

Solution Fund programs to increase outreach, referral, enrollment, and support for families of color and those

who speak a language other than English in the home, including parent ambassadors, peer support,

mentorship, and advocacy leadership programs.

Type Administrative and/or legislative

Additional authority or funding may be needed for new initiatives

EQ2. Partner with higher education to recruit and train individuals from historically underserved and immigrant communities to join the EI workforce

Issue The El workforce is disproportionately white, whereas the population of children and families

participating in Part C EI represents the racial and cultural diversity of Pennsylvania families with young children. EI is not attracting sufficient numbers of professionals from historically underserved

and racially and ethnically diverse communities.

Solution Work with higher education training programs, scholarships, and loan repayment options (including

LEND, a federally funded training initiative), to recruit and train individuals from historically

underserved communities or emerging immigrant populations to work in common categories of EI

service delivery.

Type Administrative and/or legislative

Additional funding may be needed

EQ3. Introduce Early Intervention as a career opportunity to participating families, the child care workforce, and during high school

Issue The EI workforce is disproportionately white, whereas the population of children and families

participating in Part C EI represents the racial and cultural diversity of Pennsylvania families with young children. Part C EI is not attracting sufficient numbers of professionals from historically

underserved and racially and ethnically diverse communities.

Solution Introduce early intervention as a career opportunity, and provide support for recruitment of family

members who have participated in EI and people from the early care and education workforce, and

introduce EI as a career path during high school.

Type Administrative and/or legislative

Additional funding may be needed

EQ4. Provide ongoing anti-bias, cultural responsiveness, and equity workforce development

Issue El professionals report that understanding implicit bias and improving their knowledge of the wide

range of cultural practices will support them to ensure effective, high-quality Part C EI service

delivery.

Solution Support ongoing professional development and coaching for existing workforce regarding anti-bias,

cultural responsiveness, and respect to advance equity.

Type Administrative

Limited financial impact as this can be incorporated in El Technical Assistance

EQ5. Increase county-level data by race and ethnicity

Issue There is a limited ability to monitor equitable implementation and performance of Part C EI as

essential county-level data is not available by race/ethnicity.

Solution Collect and report more county-level data by race/ethnicity related to all aspects of Early

Intervention (e.g., referral, enrollment, drop-out, completion, STAR level of child care program, etc.) of

children/families and EI workforce.

Type Administrative

Minimal additional funding needed

Addressing mental health needs of infants and toddlers in Part C El

Federal and state Part C EI laws include a focus on development in social-emotional-mental-behavioral health (SEMBH). In this review process, parents and providers reported concerns in the Part C EI screening, evaluation, and IFSP processes with regard to SEMBH. Widespread among participants was a perceived lack of sufficient focus and effective action on SEMBH that will require state and local improvements.

Discussions also highlighted how families of infants and toddlers with SEMBH needs often fall through the cracks between the Part C EI and the mental health systems. A lack of community-level coordination is one factor, with structures inside and outside government falling short. County agencies have the opportunity to strengthen collaboration, creating stronger referral pathways to available services in both Part C EI and the mental health system.

Participants also raised the insufficient supply of professionals trained in infant and early childhood mental health (IECMH) available to support Part C EI and other system needs. While Pennsylvania has a program to train and use IECMH-trained professionals, more can be done to support families and their providers in Part C El. In particular, participants recommended increased IECMH training and credentialing opportunities and IECMH consultation supports targeted to the EI workforce. IECMH consultants, in particular, can partner with the El providers in the evaluation process and in service delivery. By tailoring consultation support to the El workforce, Pennsylvania can build on its efforts using IECMH consultants to support the work of early care and education, home visiting, health, and other sectors. An evaluation of Pennsylvania's IECMH Consultation program found significant positive impacts on young children and teachers in early care and education. An expanded workforce of IECMH consultants could advise Part C EI providers on how to better address families' needs in terms of SEMBH.

What does research say about this topic?

Importance of social-emotional development:

Research confirms that young children's social-emotional development is a key component of school readiness and is a key building block for cognitive development, learning, and future mental health. It is one of the four traditional key domains of young child development. Social-emotional development also has long-term effects on success in school, work, and relationships. Family context, biological and medical conditions, and community context all can make a difference in social-emotional development. (Berry et al., 2021 https://link.springer.com/article/10.1007/s11920-021-01240-0; Johnson et al., 2020; Goodman, 2019 https://doi.org/10.1016/j.apnu.2019.01.010)

Part C and SEMBH: Social-emotional development is one of the areas specified for developmental delays or disabilities that can lead to eligibility for Part C services. While every state participating in Part C must provide services in the domain of socialemotional development to children with a delay or disability (or at risk of delay at their option), the criteria and definitions for social-emotional delays vary across states. National surveys and other studies indicate that a small proportion of children become eligible based on social-emotional delays and few social-emotional and behavioral services are delivered under Part C. For young children and their families, an array of programs and services exist that are designed as early intervention to address identified risks or as early childhood mental health treatment. In addition to Part C, states can finance early childhood mental health treatment using Medicaid. (Thomson et al., 2019 https://doi. org/10.1001/jamanetworkopen.2018.6694; Smith et al., 2018; Stein et al., 2018 https://doi.org/10.1097/ DBP.00000000000546; Zeanah & Lieberman, 2016 https://doi.org/10.1002/imhj.21590)

Screening for social-emotional development:

The Bright Futures Guidelines for preventive pediatric health care—developed and endorsed

by the American Academy of Pediatrics (AAP) and the federal government—set out a recommended schedule for well-child visits. Screening for socialemotional development is a recommended part of these visits. For infants and toddlers birth to three, specifically, the Bright Futures recommended schedule includes screening with an objective and validated screening tool for: general development; Autism Spectrum Disorder: and maternal depression at select well-child visits. In addition, assessment for social-emotional development and psychosocial needs is recommended at all 15 visits from birth to the sixth birthday. Specific studies suggest that the rates of screening for social-emotional development and maternal depression are improving but performance is still below optimal levels. (American Academy of Pediatrics, STAR; Hirai et al., 2018 https:// doi.org/10.1001/jamapediatrics.2018.1524; Tandon, 2017 https://doi.org/10.1016/j.chc.2017.04.001; American Academy of Pediatrics, 2009 https://doi. org/10.1542/peds.2009-1061)

IECMH Consultation: The role of infant and early childhood mental health consultants has grown in recent years. IECMH consultation uses mental health professionals with early childhood training to partner with other providers in early care and education, home visiting, health care, and child welfare programs. Research on IECMH consultation shows effectiveness in supporting early care and education and other providers' responses to SEMBH conditions for young children. Specifically, IECMH consultation is associated with improved social-emotional development, increased use of best practices, and greater overall program responses to SEMBH needs. (Davis et al., 2021 https://doi.org/10.1002/imhj.21889; Kniegge-Tucker et al., 2020 https://doi.org/10.1002/ imhj.21865; Georgetown University, 2019; Lambarth & Green, 2019 https://doi.org/10.1002/imhj.21818; Davis et al., 2019 Davis & Perry, 2016 Gilliam et al., 2016 https://doi.org/10.1016/j.jaac.2016.06.006; Center of Excellence for Infant and Early Childhood Mental Health Consultation; Administration for Children and Families; National Center for Children in Poverty)

Issues and Solutions related to Mental Health

MH1. Ensure social-emotional-mental-behavioral health (SEMBH) is integrated into all El processes—from the Multidisciplinary Evaluation, to the Individualized Family Service Plans (IFSP), and ultimately the services provided

Issue Federal and state Part C EI laws include a focus on development in social-emotional-mental health.

In terms of social-emotional-mental-behavioral health, however, parents and providers reported gaps

in screening, evaluation, and IFSPs.

Solution Ensure social-emotional-mental-behavioral health (SEMBH) is included in each of these Part C

processes: all multidisciplinary evaluations (MDE) as part of determining eligibility; social-emotional-behavioral health as a standard component of IFSP; and SEMBH services are included in the IFSP and

are delivered to infants and toddlers in a timely manner.

Type Administrative

Some new funding needed

MH2. Ensure county MH/DD agencies are creating a clear pathway to early childhood mental health services, whether through Part C or other mental health services

Issue El providers and other stakeholders report local level gaps between Part C and mental health (MH)

services. The effectiveness of operations varies among counties. Opportunities exist to structure

closer collaboration and referral pathways and provide greater consistency and equity.

Solution Ensure the county agencies responsible for Part C and MH/DD collaborate to develop capacity to

support very young children eligible for MH services and are linking and creating a clear pathway to

access Part C and SEMBH services (e.g., using oversight, contracts, data, financing, etc.).

Type Administrative

Minimal additional funding involved

MH3. Increase opportunities for service coordinators and EI providers to obtain the infant-early childhood mental health (IECMH) credential

Issue Current workforce capacity is insufficient to ensure access to social-emotional-mental health

services for infants and toddlers.

Solution Increase participation of the EI workforce (service coordinators and EI providers) in the infant-early

childhood mental health (IECMH) training and credentialing process and support their continued

professional development.

Type Administrative and legislative

Additional financial resources required

MH4. Include IECMH consultants as part of evaluation and service delivery

ISSUE IECMH consultants can advise other providers and programs about how best to address families'

needs in terms of SEMBH. In particular, support is needed from IECMH consultants to providers and

service coordinators in the Part C EI program.

Solution Deploy IECMH consultants, including service coordinators and providers that have completed the

IECMH credential, to partner with the EI workforce in the evaluation process and in service delivery to

ensure that EI therapists and service coordinators get the benefit of IECMH consultation.

Type Administrative and legislative

Additional financial resources required

Partnering with Medicaid to improve Part C EI

Overall, nearly half (46 percent) of all Pennsylvania children are covered by Medicaid or the Children's Health Insurance Program (CHIP). Approximately 1.3 million children under age 21 were covered by Medicaid in Pennsylvania in 2019, including more than 200,000 infants and toddlers. High levels of Medicaid enrollment are common across the country, primarily because low-income families are more likely to have young children and Medicaid income eligibility levels for children are now set above extreme poverty levels. In Pennsylvania, the Medicaid income eligibility level is 220 percent of the federal poverty level for infants under one and 162 percent of the poverty level for children ages 1 through 5. Nationally, nearly half of all children with special health care needs are covered by Medicaid, many of whom are also enrolled in IDEA Part C or IDEA special education programs.

Unlike federal IDEA Part C funds, which are capped, the federal government pays approximately half of the cost of qualifying services provided to every Medicaid-enrolled child, as defined by state law/ DHS Office of Medical Assistance Programs. This offers an opportunity to ensure federal matching dollars are maximized so that limited Part C dollars may be best targeted to ensure funding for services not covered by Medicaid reimbursement, services for children who do not qualify for Medicaid, or state infrastructure investments in quality and access. In Pennsylvania and many other states, Medicaid financing is braided with federal Part C EI funds and other dollars to finance the EI services. Pennsylvania has a unique Infant, Toddler, and Family Medicaid waiver program which provides financing for select El services to more than 2,000 Medicaid beneficiary infants and toddlers with intellectual disabilities and developmental disabilities who would otherwise require care in an institutional setting. In addition,



Medicaid is the primary source of coverage for <u>home</u> <u>and community-based services</u> (HCBS) for people—including children—with disabilities, often under waiver programs.

In a majority of states, health care for most Medicaidenrolled children occurs through managed care arrangements. Managed care means that the state Medicaid agency pays private insurers, called managed care organizations (MCOs), to manage the health care needs of Medicaid beneficiaries who elect their MCO. MCOs negotiate with and reimburse health providers as detailed in a contract with the state. Some services or programs may fall outside of managed care arrangements, with reimbursements to providers administered directly from the state on a fee-for-service basis. In Pennsylvania, most Medicaid health services for children are financed under MCOs, but EI services are reimbursed separately by Medicaid on a fee-for-service basis. In effect, this means that MCOs are responsible for ensuring children are screened for delays during well-child visits and referred to EI as those screenings identify a potential need. If enrolled in EI, qualifying IFSP services are reimbursed directly to providers on a fee-for-service basis.

The care experience and outcomes of children in Medicaid vary by state. In Pennsylvania, the percentage of children in Medicaid who had at least

6 well-child visits in the first 15 months of life is above the national average and the level of the top quartile in performance among all 50 states. In addition, Pennsylvania is among 8 states where Medicaid requires maternal depression screenings as part of a well-child visit (others include Georgia, Maryland, Michigan, Mississippi, New Jersey, New Mexico, Washington). A smaller number of states, including Pennsylvania, use performance measures to track maternal health screenings during well-child visits (including Oregon, Rhode Island, and Wisconsin). Measuring performance is an important aspect of Medicaid managed care arrangements and is detailed in state contracts and quality initiatives with managed care organizations (MCOs), physicians, and other service providers, including El.

What does research say about this topic?

Medicaid's role in financing Part C: Since the inception of the Part C El program in 1986, the intent of federal law has been for states to finance El services through a variety of public and private sources. In 1988, federal law was clarified to state that Medicaid could be used to finance Part C EI services that are part of the child's IFSP. (Public Law 100-360) The Early Periodic Screening, Diagnostic, and Treatment (EPSDT) child health benefit, requires state Medicaid programs to cover all services "necessary...to correct or ameliorate... physical and mental... conditions." Under this broad federal definition. Medicaid can and does finance El services. Medicaid is the only source of health coverage for nearly four in ten children in Part C EI and other IDEA special education programs. Surveys and studies point to a difference in performance between states that use Medicaid financing and those that do not, in terms of both access to and quality of Part C El services. (Centers for Medicare and Medicaid Services EPSDT; Williams & Musumeci, 2021; Musumeci & Chidambaram, 2019; Vail et al., 2018 https://doi.org/10.1177/1053815118771388; Centers for Medicare and Medicaid Service, 2014 Fox et al,. 1998; Federal Regulations 34 CFR Section 303.510)

Medicaid and Part C coordination and partnerships:

To ensure children receive timely access to services, Medicaid and Part C El agencies must design processes for both health and EI providers to deliver developmental screening, referral, and follow-up services in an effective and coordinated manner. Strong partnerships between Medicaid and El agencies can facilitate coordination of services and efficiency of processes, helping Part C EI programs adhere to federally mandated timelines and enabling children and families to receive more timely services. Strong partnerships between these agencies are also needed to avoid excess costs that result from duplicative services. States are required under federal law to have formal interagency agreements that define fiscal responsibilities. (Williams & Musumeci, 2021; Johnson & Bruner, 2018; Heider, 2016; Health Resources and Services Administration **EPSDT Interagency Partnerships**)

Medicaid Home and Community-Based Services:

In every state, Medicaid is the primary source of coverage for home and community-based services (HCBS) for people—including children—with disabilities, often under waiver programs. These HCBS help to ensure that children can live at home with their families rather than living in more costly institutions. In every state, various state options and waivers are used to structure Medicaid financing of HCBS. This began with the Katie Beckett program, signed into law in 1981 that enables HCBS for children up to age 19 who would otherwise have required institutionalization to become Medicaid eligible. In 2021, the American Rescue Plan Act (ARPA) made important changes including an increased Medicaid Federal Medical Assistance Percentage (FMAP) matching for states to strengthen the direct care workforce, eligibility, and the quality of HCBS. Further federal policy changes are under discussion. (Centers for Medicare and Medicaid Services HCBS; Centers for Medicare and Medicaid Services 1915(c) Waivers; Watts et al., 2020; MACPAC, 2019; Leslie et al., https://doi.org/10.1097/MLR.000000000000621)

Issues and Solutions related to Mental Health

MA1. Study the adequacy of rates and take action to address identified problems, providing for routine rate review and adjustments

Issue Providers have raised questions about the adequacy of Part C EI provider payment rates in Medicaid

to ensure quality and sustainability of the system. Given a recent increase in rates, a study of current rates can help to identify problems and areas for action. In addition, a process for routine review and

adjustment of rates is warranted.

Solution Study the adequacy of rates to cover the cost of EI services, including the impact of recent rate

increases, and take action to address identified problems; and provide for routine rate review and

adjustment.

Type Administrative

Additional funding needed

MA2. Use Medicaid data to address variations in utilization and spending for Early Intervention services

Issue Pennsylvania is making substantial investments of Medicaid funding into Part C EI. Due to lack

of publicly available data, however, there is limited understanding about Medicaid spending and

utilization patterns for infants and toddlers in the Part C EI system.

Solution Use Medicaid data to understand and address variations in utilization and spending for EI services,

including monitoring the impact of changes in Medicaid administrative claims by counties.

Type Administrative

Some new funding needed

MA4. Leverage Medicaid MCO contracts and quality/performance initiatives to stimulate pediatric primary care developmental screening and referrals

Issue The state and Medicaid providers have set a priority on developmental screening in pediatric primary

care. However, providers and families report continued gaps in screening and referrals to Part C EI. Missed opportunities exist to use MCO contracts and other mechanisms to improve developmental

screening and referrals.

Solution Leverage Medicaid MCO contracts and quality/performance initiatives to stimulate both pediatric

primary care developmental screening (based on national recommendations) and referrals to Part C

El, including data-driven quality improvement, training, and performance incentives.

Type Administrative

Minimal additional funding needed

MA3. Leverage Medicaid MCO quality/performance initiatives to increase maternal depression screening and referrals

Issue The federal Centers for Medicare and Medicaid, as well as professional associations, give priority

to maternal depression screening in pediatric primary care visits. However, providers and families report continued gaps in screening and referrals to Part C EI. Missed opportunities exist to use MCO contracts and other mechanisms to improve maternal depression screening and to make appropriate

referrals for mothers and infants and toddlers.

Solution Leverage Medicaid MCO contracts and quality/performance initiatives to increase maternal

depression screening (based on national recommendations) and referrals to Part C El.

Type Administrative

Minimal additional funding needed

MA5. Use increased federal funding for Medicaid home and community-based services (HCBS) to enlarge support for infants and toddlers with disabilities

Issue Medicaid is the primary source of funding for HCBS for people with disabilities, including children,

in Pennsylvania and most states. Federal funding to states increased under the American Rescue Plan Act (ARPA) and further investments are under discussion by Congress. With additional funds, Pennsylvania can continue its investments in HCBS for children and in Part C EI for infants and

toddlers.

Solution Use increased federal funding for Medicaid home and community-based services (HCBS) to enlarge

support for infants and toddlers with disabilities (e.g., workforce development, rates, mental health).

Type Administrative and legislative

Decisions on allocation of any new federal financial resources required









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