

A ROADMAP FOR ADVANCING FAMILY-ENGAGED DEVELOPMENTAL MONITORING



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THE HELP ME GROW NATIONAL CENTER

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CONTENTS

Executive Summary	4
Introduction	6
The Origin and Purpose of the Roadmap	6
Using the Roadmap	8
A Vision for the Future	9
The Evolution of Early Identification	10
Defining Family-Engaged Developmental Monitoring	12
Family-Engaged Developmental Monitoring	12
Is FEDM Different Than Developmental Monitoring/Surveillance?	13
Family-Engaged Developmental Monitoring: Benefits to Families	14
Family-Engaged Developmental Monitoring in Action	15
What Does FEDM Look Like?	15
Family-Engaged Developmental Monitoring Self-Assessment	17
Data Collection to Support FEDM Implementation	20
The Case for Family-Engaged Developmental Monitoring	21
Family-Engaged Developmental Monitoring Can Support Developmental Outcomes	21
Family-Engaged Developmental Monitoring Can Support Early Identification	22
Family-Engaged Developmental Monitoring Can Be Practiced Across Providers	23
Family-Engaged Developmental Monitoring Can Advance Equity	23

CONTENTS

A Framework for Children’s Healthy Development and Family Well-being	25
Component 1: Developmental Promotion	27
Component 2: Family-Engaged Developmental Monitoring (FEDM)	27
Component 3: Developmental and Autism Screening	28
Component 4: Referral for Services	28
Component 5: Receipt of Services	29
Evaluating FEDM’s Impact on Screening, Referral and Linkage	31
A Path Forward	33
Contributors	35
The Help Me Grow National Center	35
The Association of University Centers on Disabilities	36
Acknowledgements	37
Advisory Committee for the Coordinated and Integrated Data Systems for Early Identification Project	37
HMG Affiliate Work Group for the Coordinated and Integrated Data Systems for Early Identification Project	37
Appendix A. Background of the Roadmap	39
Appendix B: References	41

01

EXECUTIVE SUMMARY

The purpose of A Roadmap for Advancing Family-Engaged Developmental Monitoring (the Roadmap) is to introduce and describe family-engaged developmental monitoring (FEDM) as a key component of a framework for children’s healthy development and family well-being that includes developmental promotion, FEDM, screening, referral, and receipt of services. The concepts presented herein are based on the evidence-based assumption that children who may qualify for criteria-based developmental support programs like Individuals with Disabilities Act (IDEA) Parts C and B represent a subset of the children that are at risk for delay and adverse outcomes; therefore, universal processes should be in place to engage with families to promote positive development and proactively elicit concerns and risk factors. The Roadmap is intended for use by providers and leaders at the program or system-level in the early childhood field (defined as all those that serve and interact with young children inclusive of medical, education, social service, community-based, faith-based, and other child serving sectors). The Roadmap offers opportunities to support FEDM at the program/practice and system-levels.

FEDM is defined as an intentional partnership of families and providers working to highlight a child’s developmental progress and identify opportunities for support and education for positive outcomes. The three essential attributes of FEDM include:

1. Families are regarded as the expert on their child’s development
2. Information is gathered to inform a holistic approach to the child’s development
3. Developmental progress and needs are discussed over time

FEDM encompasses and expands upon the existing practices of developmental monitoring and surveillance in clinical and non-clinical settings to establish a shared understanding of best practice across the early childhood field and the families it serves. Inclusion of “family-engaged” in the terminology centers families as experts about their child and equal partners in the process. The expanded definition of FEDM codifies best practice, affirming a family-driven, asset-based approach that recognizes what is going well and identifies families’ priorities for their children, inclusive of risk

factors like social drivers of health. The Roadmap includes evidence-informed strategies for both families and providers, and provides self-assessments to determine the extent to which providers, programs and systems are practicing FEDM.

The premise that FEDM supports developmental outcomes is grounded in theory, research, and federal guidance. Strengths of utilizing FEDM include:

- Fostering protective factors
- Creating a multi-faceted, longitudinal picture of a child's development
- Offering a more comprehensive cross-sector and whole-family approach carried out through ongoing and routine processes to address children's needs early, regardless of the service setting
- Increasing the likelihood of identifying children at-risk for developmental delay, allowing for timely connection to supportive services to support a healthy developmental trajectory
- Being more culturally informed and accessible than screening, evaluation, and referral to traditional IDEA services

By clarifying the terminology and definition of family-engaged developmental monitoring and what it looks like in practice, the Roadmap can help programs and systems that serve families with young children to utilize FEDM strategies as part of their work in a more standardized way. The Roadmap acts as a first step on a path towards a coordinated and integrated data system for early intervention that fosters positive outcomes for young children and their families.



02

INTRODUCTION

The Origin and Purpose of the Roadmap

The purpose of The Roadmap is to introduce and describe family-engaged developmental monitoring (FEDM) as a key component of **a framework for children’s healthy development and family well-being***. The Roadmap is designed to build a foundational understanding of what FEDM is, how programs can utilize it, and how it fits into an overall framework of children’s healthy development and family well-being.

★ A FRAMEWORK FOR CHILDREN’S HEALTHY DEVELOPMENT AND FAMILY WELL-BEING

This Roadmap refers to family-engaged developmental monitoring as part of a framework for children’s healthy development and family well-being.

The framework has five components:

1. Developmental promotion
2. Family-engaged developmental monitoring
3. Developmental and autism screening
4. Referral for services
5. Receipt of services

This framework is grounded in the research and literature on developmental systems and family-centered practices. It centers families as leaders in their own child’s development and recognizes that early identification of developmental delays and disabilities is part of an approach that prioritizes promoting positive developmental outcomes.

See [page 26](#) for more information on the framework and its components

The Roadmap is a product of the Coordinated and Integrated Data Systems for Early Identification (CIDSEI) project (Appendix A). The CIDSEI project developed from a needs assessment that indicated limited ability across the early childhood sector to use early identification data to ensure young children and their families received services when needed. To address this issue, over the course of 2021-2022 the CIDSEI project aimed to explore and enhance state and territory capacity to improve the collection, management, interpretation, and dissemination of data related to developmental progress and early identification of young children with developmental delays or disabilities. This work aimed to support states and territories in their efforts to better identify areas of improvement to inform policies and practice.

The landscape scan conducted as part of the CIDSEI project (see Appendix A for details) found that while many early childhood programs and systems provide services to support early identification of delays and disorders, their focus is on screening, referral, and receipt of early intervention services. In the research literature there is a dearth of information on developmental monitoring when compared to screening^{1,2} and one reason may be that screening, referral, and linkage activities are better defined than the activities associated with developmental monitoring. The landscape scan also indicated there was a lack of shared understanding of developmental monitoring, as well as no universal strategies to employ its associated activities, and no standard metric for measuring those activities or their impact. To address this gap, the Roadmap aims to establish:

- What FEDM is
- What FEDM looks like in practice
- Why FEDM is important for child and family outcomes



Using the Roadmap

This Roadmap is intended for use by early childhood leaders at the program or system-level that currently engage in or oversee interactions with children and families and/or collect and analyze early identification data (inclusive of developmental promotion, family-engaged developmental monitoring, screening, referral, and receipt of services). The Roadmap offers provider-level strategies that can be supported by and influence the system-level. It is intended to serve as a tool for you, your colleagues, and your partners to develop common language and understanding about the goals and possibilities for supporting child development. As you read this Roadmap, consider how your program or system currently engages in FEDM and other components of the framework of children's healthy development and family well-being. You may see your current practices reflected in this document, as well as others that you may consider employing to enhance your efforts.

» WHAT'S AN EARLY CHILDHOOD PROVIDER?

The influences on a child's developmental health extend beyond those addressed through medical services. Families with young children interact with myriad systems and sectors that aim to address immediate to long-term needs such as development, nutrition, education, finance, social support, and many others.

For the purpose of this Roadmap, the term provider reflects all those who serve and interact with young children, inclusive of medical, education, social service, community-based, faith-based, and many other child-serving sectors. The Roadmap include strategies that can be universally applied across sectors.



A Vision for the Future

This Roadmap lays a foundation for understanding FEDM and its role within the larger framework for children's healthy development and family well-being so that FEDM can be universally implemented and measured. It is reflective of successful and promising practices existing in the early childhood field across the country and considers the most recent literature.

The ultimate vision is an early childhood system that incorporates the following shared values, ideas, and actions in order to support positive developmental outcomes for all children:

- Families are the driving force in their child's development
- Providers who interact with families with young children can engage in FEDM
- FEDM is the cornerstone of the five components of the framework for children's healthy development and family well-being
- Social drivers of health and protective factors play an integral role in developmental outcomes, and therefore, should be considered part of FEDM, as well as all other components of children's healthy development and family well-being
- Data on FEDM can support children and their families on the individual-level as well as inform population-level data and system improvement. Collecting this data may require changing policies and providing funding support to change billing codes and processes, train staff, and update data systems
- Data obtained through FEDM should be uniformly linked to the other components of the framework (developmental promotion, screening, referral, and linkage to services). Data collected across programs and states can allow for improved national understanding of - and response to - the current assets and needs of families with young children
- Supported by this data, investments should be made to ensure that early childhood systems provide culturally appropriate support (education, tools, activities, services) to families in order to promote optimal developmental outcomes

In order to improve the early childhood system, we must improve how we measure our efforts, which first requires standardized definitions and understanding. With a foundational knowledge of FEDM as well as the strategies and supports to effectively carry it out in real-time, we can improve how we work with families to help their children thrive.

03

THE EVOLUTION OF EARLY IDENTIFICATION

Historically, the focus of **early identification** has been on detecting the presence of a developmental delay or disability. However, an exclusive focus on children with delays and disorders, who meet eligibility criteria and are served through such categorical programs as IDEA Parts C and B, is insufficient as it attends to only a subset of the childhood population for whom developmental concerns suggest the need for programs and services. The process should be universal for all young children, including those without delays present but vulnerable to adverse outcomes,^{3,4} with further efforts targeted towards those at risk for delay (see Targeted Universalism on [page 25](#) for more information on this approach). Broadening the target population necessitates eliciting parent's opinions and concerns, which are highly predictive.⁵

Centering the **family voice**⁶ and experience is an evolution away from focusing on identifying specific disorders, such as autism spectrum disorder (ASD), which may not be in line with family priorities. As an example, the Centers for Disease Control and Prevention's "Learn the Signs. Act Early." (LTSAE) program implemented in 2004 originally began as a health campaign for the early identification of ASD, so families could get the supports and services they need.⁷ However, through formative research with families, the LTSAE program evolved from a singular focus on ASD to one that educates all parents about developmental monitoring.⁸

Broadening the perspective of monitoring all young children's development through parent education and input led to burgeoning evidence about the importance of family engagement in the process of early identification. For example, lines of research looking at the convergence between concerns elicited from families and screening scores demonstrate that parents are accurate reporters about their child's development.⁹ Moreover, research demonstrates that children are more likely to receive services if a concern is identified within service delivery models that routinely and actively solicit input from families.¹⁰

Expanding the early identification process to include other child and family priorities and needs, such as resources like concrete and social supports, is also a predictor of positive child outcomes.¹¹ Determining family needs and priorities to support goal-making and service delivery honors the importance of the family's values and perspective in decision-making.¹² Embedding family voice within a comprehensive and integrative process focusing on early identification can improve child and family **well-being**.¹³ Family well-being can lead to positive outcomes for all young children, especially those who experience environmental risk factors and identified delays and disorders.

★ IMPORTANT ROADMAP TERMS

Early identification: Detection of concern for developmental delay or disability. When concern is identified, families may partner with early childhood programs and systems to support their child's developmental progress and well-being.

Family: The people with whom the child has a close personal relationship and who are responsible for the well-being and development of the child.

Family voice: Families' independent representation of their knowledge, values, insights, expertise, actions, concerns, experiences, and cultural backgrounds in decision-making contexts on behalf of their own and their children's interests and/or the collective interests of parents, children, families, and parent organizations in their communities.

Holistic approach: Considers multiple factors across the social ecology that may contribute to health and well-being, including the social and environmental conditions that impact a child's development inclusive of assets and goals as well as social drivers of health and other risk factors.

Provider: All those that serve and interact with young children inclusive of medical, education, social service, community-based, faith-based, and many other child-serving sectors.

Social drivers of health (SDOH): Community and societal factors that can impact health outcomes for all people, including but not limited to economic security, access to quality education and healthcare, environmental safety, and social context. Also known as social determinants of health.

Well-being: Satisfaction with one's physical, social, emotional, intellectual, spiritual, behavioral, and economic circumstances.

04

DEFINING FAMILY-ENGAGED DEVELOPMENTAL MONITORING

Family-Engaged Developmental Monitoring

Family-engaged developmental monitoring (FEDM) is an intentional partnership of families and providers combining their knowledge to better understand a child's developmental path, including celebrating progress and identifying opportunities for support and education. From birth, and on a regular and ongoing basis, providers engage families in conversations around their child's developmental progress, well-being, and factors that impact it, such as the **social drivers of health (SDOH)**.^{14 15} During these conversations, families share information about their child's achievements, identify potential concerns or factors that might impact their child's development, and may advocate for additional resources in support of their child and family.

These ongoing and regular conversations lend helpful context for understanding the factors of a child's life that influence their development, while providing increased opportunities for **early identification** and connection to resources families may seek.

Family-engaged developmental monitoring has three essential attributes:

1. Families are regarded as the expert on their child's development¹⁶
2. Information is gathered to inform a **holistic approach**¹⁷ to the child's development¹¹
3. Developmental progress and needs are discussed over time¹⁸

Families contribute to FEDM when they share with a provider their observations, insights, and concerns about their child's development, as well as their own priorities for their child and family. While a provider may give families information, tools, tips, and activities to utilize in their own independent monitoring, FEDM refers to the contribution and use of that family knowledge toward a collaborative effort in providing support and promoting positive outcomes.

Providers engaging in FEDM seek to foster meaningful relationships with the families they serve and learn more about the child's development than what they might be able to glean through service interaction and screening. Providers actively listen and engage in conversations that prioritize what is going well in the child's development, as well as family priorities and concerns. Providers share developmental insights, affirm families' support of their children's development, and help identify opportunities for further support. As part of FEDM, providers may offer information, tools, tips, and activities for families to use at home to increase their knowledge of healthy child development and foster their child's developmental skills.

When providers practice FEDM, they intentionally establish a rapport with families that invites celebration of progress and conversations around families' needs and concerns. The ongoing practice of FEDM extends the reach of providers, and it reinforces families as skilled and knowledgeable partners in their child's development.¹⁹

Is FEDM Different Than Developmental Monitoring/Surveillance?

Family-engaged developmental monitoring is not a new or different concept; rather, it encompasses and expands upon the existing practices of developmental monitoring and surveillance^{20, 21} to establish common terminology and actions across early childhood-serving providers, and intentionally includes the phrase "family-engaged" to center families as key partners in the process. Developmental surveillance is a term typically used in the medical field and refers to providers' strategies to elicit and attend to families' opinions and concerns about their child's development as part of their ongoing interactions during service delivery.⁵ In non-clinical settings and when communicating with parents, the term developmental monitoring is more common, referring generally to the observation and tracking of developmental milestones as a child grows.²² Therefore, the term "FEDM" uses terminology more familiar to families and non-medical early childhood providers while building upon concepts adopted by the medical community and emphasizing the importance of considering families' opinions in the early detection process.

The expanded definition of FEDM codifies best practice and affirms a family-driven, asset-based approach that recognizes what is going well and identifies families' priorities for their children. Monitoring development should be inclusive of eliciting concerns and assessing for risk factors that may impact the child's development, like SDOH. Ongoing and regular conversations between families and providers generate helpful context for understanding the factors of a child's life that influence their achievement and challenges, while providing increased opportunities to connect families to resources they are seeking in support of their child.

Family-Engaged Developmental Monitoring: Benefits to Families

Partnership between families and providers is key to FEDM. Early childhood theory and research ^{23, 24, 19, 10} evidence that when families engage in developmental monitoring of their child with the support of trusted providers and resources they are:

- Knowledgeable about the developmental milestones their child is likely to achieve at specific ages
- Equipped with information, tools, and activities they can use to foster an environment that helps their child learn and develop
- Aware of risk factors and understand how their family's protective factors, ²⁵ such as their support systems, can offset potential risks
- Skilled in identifying a potential delay in milestone achievement and taking actions when there might be potential areas of concern
- Knowledgeable about where and who to turn to for resources and information that support their child and family's developmental needs
- Able to advocate for resources and services from which their child may benefit to advance in their development and well-being

★ ENGAGING FAMILIES BEYOND PARENTS

For the purposes of this Roadmap, **family** is defined as those closest to a child, which may include a combination of any of the following individuals: biological, adopted, or foster parents, and/or stepparents, aunts, uncles, grandparents and any additional extended members of the household unit who are invested in raising the child. Families can constitute a single parent, two parents, single household, or multigenerational household.

This definition is not intended to be exhaustive, but rather recognizes that the term "parent" is not inclusive of all of those that influence the life and developmental trajectory of a child, nor does it apply for many families. These other caregivers have valuable perspectives on the child's status and needs, and may play an integral role in future supports for the child.

05

FAMILY-ENGAGED DEVELOPMENTAL MONITORING IN ACTION


What Does FEDM Look Like?

Family-engaged developmental monitoring encompasses a wide range of evidence-based best practices, including: [19](#), [23](#), [26](#), [16](#), [27](#)

- Valuing families as the main source of knowledge and expertise related to their child's health and development
- Affirming and reinforcing developmental strengths in the child's life, thereby creating a positive feedback loop of family-driven activities that support positive developmental outcomes
- Utilizing monitoring tools such as the CDC's *Learn the Signs. Act Early.* developmental milestone checklist to facilitate conversations
- Documenting the child's current skills, abilities, and milestones, and any or all concerns about development or social drivers of health, and paying equal attention to both developmental progress and concerns
- Gathering and documenting both risk factors and protective factors in the child's growth environment at the family and community-level, and asking caregivers if or how they see risk factors or protective factors shaping their child's developmental progress
- Eliciting family priorities, especially when more than one need is identified or shared
- Asking caregivers longitudinal questions, such as how they see progress or concerns changing over time and revisiting priorities, questions, and concerns at later points

- Asking caregivers about what other programs or providers say about their child’s development; when useful, ask permission to share or request information with those programs to get a more varied perspective of the child or family across time or topics
- Continuing to monitor throughout screening, referral, and receipt of services (if screening and services are determined as appropriate by the provider and family)
- Recognizing and addressing cultural considerations and language access needs

Attributes of Family-Engaged Developmental Monitoring

<p>Family Strategies</p> <ul style="list-style-type: none"> • Families share observations and opinions about child’s skills/behavior • Families voice what healthy development means to them or what they feel their child needs right now 	 <p>Families are regarded as the expert on their child’s development</p>	<p>Provider Strategies</p> <ul style="list-style-type: none"> • Providers elicit family goals, questions, and concerns routinely • Providers ask family opinion of their child’s development • Providers identify parent priorities - for growth and support
<ul style="list-style-type: none"> • Families learn about factors that support or hinder development • Families gather perspectives from multiple adults or programs who interact with their children 	 <p>Information is gathered to inform a holistic approach to the child’s development</p>	<ul style="list-style-type: none"> • Providers gather information about family strengths, risk factors, etc. • Providers ask about other program/provider insights from families directly or from other providers who support them
<ul style="list-style-type: none"> • Families note and reflect on their children’s development over time (tools can be helpful!) • Families share how long any risk factors or concerns have been present • Families revisit questions or progress with the same provider 	 <p>Development is discussed over time</p>	<ul style="list-style-type: none"> • Providers ask families how their child’s development or their own concerns have changed over time • Providers re-engage with the family to revisit questions, concerns, and developmental progress

Family-Engaged Developmental Monitoring Self-Assessment

The Family-Engaged Developmental Monitoring Self-Assessment for Early Childhood Programs and Providers aims to help professionals, programs, and systems assess the extent to which they are practicing FEDM and identify opportunities to enhance existing efforts.

This self-assessment is a guide to help providers and programs understand what FEDM looks like in practice. It is grounded in the defining characteristics of developmental monitoring, ecological theory,²⁸ empirical evidence on family-centered practices,¹⁹ and developmental systems approach.¹¹ The prompts included in the self-assessment can assist programs and systems in identifying where their existing service delivery aligns with FEDM and where practice could be strengthened as part of a larger framework of children's healthy development and family well-being.

The Family-Engaged Developmental Monitoring Self-Assessment for Early Childhood Systems is a guide to scaffold leaders' understanding of what FEDM looks like at the system-level. Early childhood system-builders have a unique role in creating effective and efficient networks of support for providers to plug into and reduce the barriers families face in accessing supports and services they determine to be important and necessary for their child's development and family well-being. FEDM is a strategy that system-builders can leverage to ensure that their integral stakeholders are working together to determine goals, priorities, and supports necessary for children's healthy development.



**A FAMILY-ENGAGED DEVELOPMENTAL MONITORING SELF-ASSESSMENT
FOR EARLY CHILDHOOD PROGRAMS AND PROVIDERS**

Each of the FEDM attributes below have critical questions to consider.
Review each question and mark (✓) for those that are currently being achieved within your early childhood program or medical practice.

✓	PRACTICE
Families are regarded as the expert on their child's development	
	Do you celebrate milestones with families as they share their child's strengths?
	Do you directly and routinely elicit parent priorities, concerns, and questions?
	Do you allow information provided by the family to shape your view of the child?
	If a family's views of the child's development does not align with your own, do you ask clarifying questions to better understand factors that may contribute to the difference?
	Does a family's priority for concerns or support shape your considerations for future support?
Information is compiled to inform a holistic approach to the child's development	
Depending upon your professional or programmatic scope, do you gather information about the child's:	
	Family-level support network, such as family or community members who interact positively with the child, who support the family in times of need?
	Community-level support network, such as faith-based organizations?
	Involvement in other programs or services, such as: early care and education programs, parent education or support groups, food banks?
	Family-level risk factors, such as a child's underlying health conditions, family-level trauma, parental mental health, or substance use?
	Community -level risk factors, such as neighborhood violence, discrimination in service access or delivery, poverty?
	Positive parenting practices, such as reading together, serve-and-return interactions, creating rich opportunities for play?
	Basic needs, such as food insecurity, access to medical care, unemployment, and housing?
Development is discussed over time	
	Do you routinely elicit information on progress and concerns?
	Do you ask families how they have seen their child progress over time?
	Do you ask families how long a concern has been present or if it has changed over time?
	Do you ask families how they see a given risk factor or asset has shaped the child's growth?
	Do you directly and routinely revisit the progress, social and environmental conditions, and concerns at a future visit?
	Do you, with family consent, elicit and share information with other providers for a more holistic approach to serving the family?
	Do you follow-up with families regarding their priorities, concerns, and questions?

A FAMILY-ENGAGED DEVELOPMENTAL MONITORING SELF-ASSESSMENT FOR EARLY CHILDHOOD SYSTEMS

Each of the FEDM attributes below have critical questions to consider. Review each question and mark (✓) for those that are currently being achieved within your early childhood systems.

✓	PRACTICE
Families are regarded as the expert on their child’s development	
	Are families’ priorities, concerns, questions and feedback on programs used to inform systems design and improvement?
	Do you include families in advocacy and policy work?
	Are families represented on your leadership or decision-making teams?
	Are partners trained on how to elicit parent priorities, concerns, and questions directly and routinely?
	When partners elicit parent priorities, concerns, and questions, are they shared alongside other contextual information and referrals?
Information is compiled to inform a holistic approach to the child’s development	
	Are family’s culture, language and lived experience incorporated into your decision making?
	Are your partnerships reflective of the priorities and needs of families in your community or state?
<i>Does your system have the ability to collect, monitor, and analyze information about:</i>	
	Family-level support network, such as family or community members who interact positively with the child, who support the family in times of need?
	Community-level support network, such as faith-based organizations?
	Involvement in other programs or services, such as: early care and education programs, parent education or support groups, food banks?
	Family-level risk factors, such as a child’s underlying health conditions, family-level trauma, parental mental health or substance use?
	Community or societal-level risk factors, such as neighborhood violence, discrimination in service access or delivery, poverty?
	Positive parenting practices, such as reading together, serve-and-return interactions, creating rich opportunities for play?
	Basic needs, such as food insecurity, access to medical care, unemployment and housing?
Development is discussed over time	
	Does your system have the ability to document, monitor, and analyze family responses longitudinally to questions such as: <ul style="list-style-type: none"> • Family-level goals and priorities? • Information on progress or concerns at every interaction/visit? • What risk factors or assets are present? • How long a concern has been present?
	Is data collected over time and used to inform the community about gaps, barriers, challenges, and opportunities to strengthen the early childhood system and advocate for community change?

Data Collection to Support FEDM Implementation

As with all best practices, data collection helps measure key activities to determine whether a program activity is implemented fully and its outcomes add value. No single metric can capture family-engaged developmental monitoring, but programs can consider data points currently collected or those that might be feasible to introduce into their work flow at each critical point a family engages with the system to:

- Confirm that a strategy is done routinely
- Capture holistic information about the child so it is utilized in later conversations
- Capture family priorities and goals to be utilized in later conversations

Future work may include developing tools to track this information systematically across sectors. See [Evaluating FEDM's Impact on Screening, Referral, and Linkage on Page 31](#) for more considerations and implications.



06

THE CASE FOR FAMILY-ENGAGED DEVELOPMENTAL MONITORING

Family-Engaged Developmental Monitoring Can Support Developmental Outcomes

The premise that FEDM supports developmental outcomes is grounded in theory, research, and federal guidance.^{23, 26, 19, 29} Families observe the ongoing changes in the development and health of their children. This close relationship allows for family members to celebrate milestones and identify areas of concern in real-time. Additionally, families themselves know better than anyone else the impact of social and environmental conditions that their child and family experience from day to day. Family-engaged developmental monitoring leverages the intimate knowledge families have of their children and circumstances, and pairs that with enhanced skills to better understand and advocate for what their children need developmentally, socially, physically, and environmentally in order to grow to their fullest potential.

FEDM promotes child development by enhancing protective factors. The research-informed Strengthening Families Framework outlines five protective factors that both reduce the likelihood of child abuse and neglect and promote a family environment that fosters optimal child development: parental resilience, social connections, concrete support in times of need, knowledge of parenting and child development, and social and emotional competence of children.³⁰ The activities that compose FEDM - engaging in activities that support development, reviewing strengths and concerns, connecting to meaningful supports - align directly with many of these protective factors.

Family-Engaged Developmental Monitoring Can Support Early Identification

Common practice for identifying early childhood developmental delays frequently sees children through a normative lens, comparing individuals to the outcomes of others by asking the question, “Is this child far enough behind their peers to warrant intervention services?” This narrowly-scoped question is at odds with the known benefits of prevention and in isolation of the predictive value of parent concern, and the social drivers of early childhood development.^{31, 32} From a life course perspective, creating a multi-faceted, longitudinal picture of a child’s growth is proactive and relevant to changing long-term outcomes.³³ Family-engaged developmental monitoring invites providers to gather and synthesize an inclusive set of data to optimally support a child’s development routinely and continuously. It also offers the opportunity for a more comprehensive cross-sector and holistic approach carried out through ongoing and routine processes to address children’s needs early, regardless of the service setting.

When the myriad providers that serve families with young children participate in FEDM, they take an active stance in:

- Eliciting relevant information directly from families on a child’s developmental progress, concerns, and family priorities
- Documenting meaningful information for individual family support
- Utilizing those data points captured through ongoing engagement to inform service delivery (by their own program or in collaboration with fellow service providers)

While some screening tools are designed to capture similar holistic information about a child, their family, and community, screening alone does not provide the inclusive, comprehensive context needed to increase the likelihood of children receiving necessary early intervention services. When family-engaged developmental monitoring is practiced in complement to systematized processes such as screening, referral, and linkage, families are supported over time and more able to utilize their power to observe and identify concerns and advocate on behalf of their priorities, goals, and needs. Indeed, using both monitoring and screening can increase the likelihood of a child receiving necessary early intervention services than screening alone.¹ In conjunction with screening, wider implementation and measurement of FEDM can further define this relationship to support positive child outcomes.

Family-Engaged Developmental Monitoring Can Be Practiced Across Providers

The influences on a child’s development extend beyond those addressed through health services.¹⁹ Children and families interact with myriad systems and sectors in their early years that are designed to address short and long-term priorities across many areas such as development, nutrition, education, finance, social support, and many others.^{34, 35} No one sector alone serves all children consistently and in a culturally-relevant way. Unless a child is able to access programs like Pre-K or Head Start, it is often not until formally enrolled in school (around age five) that their development and achievement is routinely observed and documented.³⁶ When children enter school with unidentified or unaddressed developmental concerns, we have missed opportunities to proactively prevent delays or ensure connection to relevant services.³⁷ While early childhood screenings (developmental, social-emotional, autism, etc.) may not be suitable for all settings, discussing a child’s developmental progress, understanding the family’s social and environmental conditions, and sharing information and activities are just some of the FEDM activities that can be employed across family and child-serving providers, making FEDM an accessible component of the framework for children’s healthy development and family well-being.

Family-Engaged Developmental Monitoring Can Advance Equity

A focus on FEDM as a crucial, ongoing component of the framework for children’s healthy development and family well-being can help re-center power in the hands of families and is a focused strategy to support Black, Indigenous, People of Color (BIPOC) and other historically underserved or marginalized families.

A history of systemic racism and bias has impacted how BIPOC families interact with early childhood systems, such as the early intervention system.³⁸ Children from families that are BIPOC, low-income, primarily speak languages other than English, or live in isolated communities are more likely to be impacted by SDOH that can in turn impact their developmental outcomes,³⁴ and racism itself is “a significant threat to healthy development and well-being.”¹⁷ Families without ample financial resources and those living in areas with a scarcity of available services face barriers to access such as high cost, insufficient linguistic services, transportation, and other logistical obstacles on top of the biases that exist within the service system.³⁹

Additionally, BIPOC families are less likely to indicate having their concerns elicited by medical providers⁴⁰ and fewer BIPOC children receive formal early intervention services, with one study demonstrating that 2 year-old Black children were five times less likely to receive IDEA Part C services than their white counterparts.^{41, 42} These differences may be attributed to implicit bias, or a set of unconscious thoughts and beliefs that affects actions, which has been shown to impact how providers serve families.^{43, 44} These biases can prevent the identification of concerns and impede connection to supportive services.

Historical, institutionalized, and structural racism, discrimination, and oppression may also prevent BIPOC families from completing screenings and/or seeking needed developmental support services altogether: for example, a child must be “labeled” so as to receive services,⁴⁰ but labeling comes with stigmatizing social connotations, and is related to a history of “tracking” BIPOC individuals as a means of segregation and subjugation.⁴⁵ Evaluation and receipt of services through a government-backed program like IDEA, therefore, may not be appropriate for all families; instead, other sources of support for promoting positive developmental outcomes and meeting family needs must be considered.

When families are centered in the prioritization, decision-making, and selection of services for their children, this expands early identification to be more inclusive and culturally appropriate.²³ Family-engaged developmental monitoring can be more culturally informed than screening, evaluation, and referral to traditional IDEA services given that it does not rely solely on methods or standardized measures that may not resonate with the family given the cultural and historical context. Moreover, leveraging **targeted universalism**,^{*46, 47} FEDM is an equity strategy that recognizes the community-based programs that historically and regularly interact with BIPOC families and their uniquely positionality to help support children’s healthy development and family well-being as trusted community partners.³⁴ Systems practicing FEDM intentionally create strategic linkages between the family’s goals, concerns, and needs and the trusted community-based supports designed to serve them.

TARGETED UNIVERSALISM

Targeted Universalism is a methodology to operationalize systems and programs that move all groups towards a determined universal goal with specific strategies tailored to different groups based on how different groups are situated within existing structures, culture, and across geographies.

07

A FRAMEWORK FOR CHILDREN'S HEALTHY DEVELOPMENT AND FAMILY WELL-BEING

The **framework for children's healthy development and family well-being** offers a conceptual model of strategies that support positive developmental outcomes and identification of developmental delays or disabilities at the youngest age possible. The framework is grounded in the research and literature on ecological theory,²⁹ family centered practices,¹⁹ and developmental systems approach.^{48, 11} It reflects an asset-based approach that prioritizes promoting positive developmental outcomes, and that families are leaders in their child's development and health and should be engaged as such. The components of the framework include activities that support children's positive and healthy development and, in doing so, allow for early identification of any developmental delays or disabilities that may emerge over time in young children.⁴⁹

The five components of the framework are:

1. Developmental promotion
2. Family-engaged developmental monitoring
3. Developmental and autism screening
4. Referral for services
5. Receipt of services

Each component of the framework articulates an active approach to support family’s priorities, celebrates children’s developmental progress, and enables the conditions for early identification of developmental delays and disability when present. Components 1-3—developmental promotion, ongoing FEDM, and routine early childhood screenings — are recommended to be carried out for all children over the course of the early childhood years. Components 4 and 5 — providing increasing supports as needed through referral to services and follow-up — may only be appropriate for some families. All family-level activities are situated within the broader context of community or societal-level effort to take a holistic approach to healthy child growth and well-being.



Component 1: Developmental Promotion

Developmental promotion encompasses universal and comprehensive strategies for families, providers, programs, and communities intended to enhance understanding of children’s development and enable the conditions that support positive child developmental and health outcomes. Through information, materials, and tools, families learn what to expect as their child grows so that they can engage their child in age-appropriate activities, celebrate milestones, and recognize when there are concerns.

Common tools and strategies used for developmental promotion include:

- Learn the Signs. Act Early. materials⁵⁰ and Milestone Tracker app
- Developmental support app/messaging services such as Vroom,⁵¹ Bright By Text,⁵² and The Basics⁵³
- Developmental health events such as Help Me Grow’s Books, Balls, and Blocks
- Resource pages and directories
- Social media promotional/informational campaigns
- Family activity materials

Component 2: Family-Engaged Developmental Monitoring (FEDM)

FEDM is an intentional partnership of families and providers working to highlight a child’s developmental progress and identify opportunities for support and education. FEDM has three essential attributes:

1. Families are regarded as the expert on their child’s development
2. Information is gathered to inform a holistic approach to the child’s development
3. Developmental progress and needs are discussed over time

See [What Does FEDM Look Like?](#) for evidence-based best practices.

Component 3: Developmental and Autism Screening

Families and providers work together to periodically complete standardized screening tools that highlight children's developmental achievements and support the identification of delays or disabilities present. Screening may take place when a family expresses a concern or at the suggestion of a provider at recommended ages as outlined by Bright Futures or similar programmatic guidelines.

Evidence-based and best practices of developmental and autism screening: ²⁰

- Using an evidence-based, validated, screening tool that is culturally appropriate
- Making the tool available in multiple languages
- Encouraging families to share both achievements and concerns related to their child's development throughout the screening process

Component 4: Referral for Services

Families are linked to trusted **supports and services*** they can rely on to help with child development, health, wellness, and family needs based on their immediate identified priorities and captured during FEDM conversations or through validated screening.

Evidence-based and best practices of referral for services: ^{23, 39, 54}

- Maintaining a comprehensive and up-to-date list of accessible services to which families can be referred
- Actively engaging the family to identify the family's priorities and match referrals to meet those priorities
- Co-determining and providing the level of support the family needs to make a successful connection to services including coordination with other programs and identifying potential barriers to accessing services
- Following up with families in a timely manner to make sure they connected with the resource for which they were referred and confirming that it is meeting their identified need

- For children not-eligible for IDEA Part C/B ensuring ongoing family-engaged developmental monitoring occurs and when possible, connection to other developmentally-appropriate services such as early care and education programs or Head Start/Early Head Start

★ SUPPORTS AND SERVICES

Supports and services to which a family or child may be referred are varied and may include:

- IDEA Part C or B (i.e. Early Intervention)
- Early childhood programs (i.e., home visiting, early care and education, Head Start/Early Head Start)
- Health services (well child visits, etc.)
- Specialized services (speech and language, mental health supports)
- Services to address basic needs (WIC, SNAP, Medicaid, transportation, etc.)

Component 5: Receipt of Services

Providers follow-up with families to ensure a successful connection to the supports and services to which they were referred and to address any remaining or new priorities they might have. If families have not been successfully connected, a new referral or other effort should be made to assist the family in getting the supports and services desired.

Evidence-based and best practices of receipt of services: [23, 55](#)

- Engaging the family in conversation about their child's developmental need to ensure understanding and support any concerns they have about what the identified delay may mean for their child
- Following-up with families to ensure successful and timely service connection
- If the child is on a wait-list, providing families with developmentally-promoting activities and additional supportive referrals to offset the delay in service

- During follow-up, asking if there are any new achievements, needs, or concerns since the last conversation with the family
- When families are referred for IDEA Part C/B services:
 - Asking the family if they have an Individualized Family Service Plan (IFSP)/Individualized Education Plan (IEP) and if they have any questions about either of those
 - Creating systematic opportunities for families to provide feedback about their experience receiving IDEA Part C/B services in order to collect information related to satisfaction, challenges, and the extent to which services are meeting the need
 - Encouraging continuous family-engaged developmental monitoring to ensure that services are adequately supporting the child's development and well-being



08

EVALUATING FEDM'S IMPACT ON SCREENING, REFERRAL, AND LINKAGE

Family-engaged developmental monitoring is a valuable activity in its own right and has the potential to improve the quality and success of developmental screening and connection to relevant referrals and services. Unlike developmental promotion, which can refer to community-level strategies for awareness and improved conditions that foster healthy development, FEDM data captures activities and insights specific to the child and their family. Family-engaged developmental monitoring practices use a responsive, proactive, ongoing dialogue with the family and can support the effective use of screening tools or successful connection to resources and services to promote both the family's well-being and the child's development.

Using the FEDM self-assessments provided in this Roadmap, programs and systems may find they are already conducting practices and collecting the data needed to understand if they are engaging in FEDM. Conversely, programs and systems may identify new practices that can support refinements to their existing process for service delivery or data collection methods.

The field of early childhood has made strides in developing uniform definitions and measures around developmental screening and service connection.⁵⁶ Indeed, many regions and states have developed, or are striving to develop, databases to advance population-level data to improve implementation and access to services for young children and families.⁵⁷ Increasingly, large funding streams and initiatives allow programs to aggregate such data across sectors, at increasing scale.⁵⁷ In some cases, these data flow into longitudinal data systems that support the evaluation of longer-term child outcomes, such as educational attainment or workforce entry.⁵⁸ At a population-level, these data can inform system improvement, public health, policy, and advocacy efforts.

Even as screening and linkage systems evolve, there is ongoing need to expand the reach and responsiveness of those services. Family-engaged developmental monitoring offers a path towards broader and more authentic engagement with families around their child's development. As our field refines its FEDM definitions, practices, and measurement, these data can be linked at the child-level to screening, referral, and linkage measures. Immediate implementation of FEDM can improve family-level outcomes by creating more opportunities for discussion, education, and addressing factors that impact child development. Data collection at the family-level can also help track progress and concerns and lead to timelier referral and linkage when indicated. At the population-level, connecting FEDM data to data on developmental promotion, screening, referral, and linkage can allow professionals to recognize trends and as a result, design system improvements and advocate for policy changes to support all families.



09

A PATH FORWARD

This Roadmap was intended to contribute to a shared, inclusive understanding of developmental monitoring and its distinct place in an overall framework of children’s healthy development and family well-being. By clarifying the terminology and definition of family-engaged developmental monitoring and what it looks like in practice, programs and systems that serve families with young children can utilize FEDM strategies as part of their work in a more standardized way. In the process of doing so, early childhood leaders can begin to track and measure FEDM. Measuring the day-to-day, child and family-level actions and impacts of FEDM can allow for aligning data across the other components and its overall impact at both the individual and population level, informing systems improvement and advocacy efforts. The Roadmap acts as a first step on a path towards a coordinated and integrated data system for early identification that fosters positive outcomes for young children and their families.














CONTRIBUTORS

The Help Me Grow National Center

Together, the [Help Me Grow \(HMG\) National Center](#) and National Affiliate Network identify solutions, raise awareness, foster partnerships, elevate the conversation to a national-level, and advance a movement dedicated to optimizing the health and development of all children. The HMG National Center works to promote the relationships, dialogue, innovation, and communication necessary to build broad-based support for the kinds of systems that support strong, connected communities and healthy families. The HMG National Affiliate Network represents an ever-growing, powerful coalition of states, communities, and individuals invested in ambitious and resourceful early childhood systems that optimally serve all families and children. The HMG National Affiliate Network consists of more than 120 individual systems across 29 states and the District of Columbia.

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Help Me Grow North Texas

Since 2019, HMG North Texas has been a proud member of HMG National Affiliate Network. As an 18 county community collaborative, HMG North Texas now stands as a replication site for the state of Texas as it works towards full implementation of the HMG Model.

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The Association of University Centers on Disabilities

[The Association of University Centers on Disabilities](#) (AUCD) is a membership organization that supports and promotes a national network of university-based interdisciplinary programs. These programs serve and are located in every U.S. state and territory and are all part of universities or medical centers. They act as a bridge between the university and the community, bringing together the resources of both to achieve meaningful change.

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Advisory Committee for the Coordinated and Integrated Data Systems for Early Identification Project

At the onset of the CIDSEI project, an Advisory Committee was established to inform this effort with representation from several early childhood organizations. The Advisory Committee met quarterly over the course of the project period. Members included:

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HMG Affiliate Work Group for the Coordinated and Integrated Data Systems for Early Identification Project

From May-August 2022, the HMG National Center convened a work group of nine HMG systems to inform the development of this resource. Members included:

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APPENDIX A.

BACKGROUND OF THE ROADMAP

The Centers for Disease Control and Prevention (CDC) “Learn the Signs. Act Early.” (LTSAE) program aims to improve early identification of developmental delays and disabilities by educating families and caregivers about developmental milestones, promoting family-provider communication about child development, and encouraging families to take action by discussing concerns with providers and receiving early intervention services as needed. The program funds Act Early Ambassadors within states and territories who work with early childhood programs to integrate the LTSAE health campaign materials and resources.

The Act Early Response to COVID-19 project was developed in September 2020 to lessen the negative effects of the COVID-19 pandemic on the early identification of developmental delays and disabilities. The project funded and supported Act Early Ambassador-led Response Teams, which are made up of representatives from different early childhood programs. The Response Teams used this support to bolster and evaluate activities to improve the early identification of developmental delays and disabilities among young children birth to age five. For the project, early identification was described as having four steps. These steps are:

1. Parent-engaged developmental monitoring
2. Developmental and autism screening
3. Referral for services
4. Receipt of early intervention

In the fall of 2020, AUCD and CDC conducted a needs assessment of the Act Early Response to COVID-19 teams to better understand the impact of the pandemic on early identification efforts. The 43 state and territory Response Teams participated in a survey (N = 397). Response Teams included state and territory Act Early Ambassadors, team leads, and multi-sector program and system administrators. Programs and systems include, but are not limited to, Title V, Healthcare, IDEA, ECCS, Early Care and Education, Child Welfare, WIC, and HMG.

One finding from the needs assessment included the absence of key data that Response Teams needed in order to monitor their early identification efforts which aimed to ensure young children and their families received services. Respondents reported varied barriers that precluded them from using data to monitor their early identification activities, including a lack of a coordinated early childhood data system, the inability to share or integrate data across programs and systems, failure to collect data, a lack of existing data, inability to access data, and a lack of a centralized data repository.

In response to this finding, the CDC's LTSAE program funded the Coordinated and Integrated Data System for Early Identification (CIDSEI) project. The project's activities included initial landscape and environmental scans to understand current early identification data collection efforts. The scans consisted of various information-gathering methods, including a review of secondary data, gray literature (i.e., briefs, reports), resources to support data system development, and key informant interviews with 19 program and system administrators from various early childhood programs nationally and internationally.

The findings from these landscape and environmental scans provide insight into how early childhood programs collect and use data for early identification, as well as how they identify priorities to support young children and their families. Key findings include the following:

- Multiple programs in different systems (i.e., health versus education) support young children and their families, making data sharing and integration challenging
- Engaging families in the process of early identification and accounting for their priorities and needs is a critical aspect of early identification
- Developmental monitoring occurs throughout the early identification process
- Ongoing developmental monitoring beyond screening and referral is especially important for children at risk for developmental concerns or those who may not qualify for IDEA Part C/B services
- Program requirements facilitate data collection around early identification
- When data is collected on developmental monitoring, the associated metrics vary significantly
- The history and context of the state or territory influence the early identification process and data collection efforts, such as data privacy laws and funding sources

The data from the scans revealed that there is no clear definition of developmental monitoring nor a single metric to measure the impact of monitoring activities on early identification. The findings also emphasized the importance of family engagement for early childhood programs in the process of early identification, including discussion of social and environmental conditions that impact development. Respondents noted that families' needs are accounted for by service delivery and data collection and how that is improved when varied programs work together; however, that does not happen universally or regularly at present. The lack of integration impedes programs' ability to share data to account for young children and families who may be receiving services from multiple programs. These findings informed the development of *A Roadmap for Advancing Family-Engaged Developmental Monitoring*.

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