Help Me Grow: So All Children Can Shine





Family Engaged Developmental Monitoring *The CIDSEI Project* September 22nd, 2022

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Part of Connecticut Children's Office for Community Child Health www.helpmegrownational.org

Agenda

- The CIDSEI partnership
- A Roadmap for Advancing Family-Engaged Developmental Monitoring
- The Framework for Children's Healthy Development and Family Wellbeing
- Panel
- A Vision for the Future

Our Presenters



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"Learn the Signs. Act Early." National Center on Birth Defects and Developmental Disabilities Centers for Disease Control and Prevention

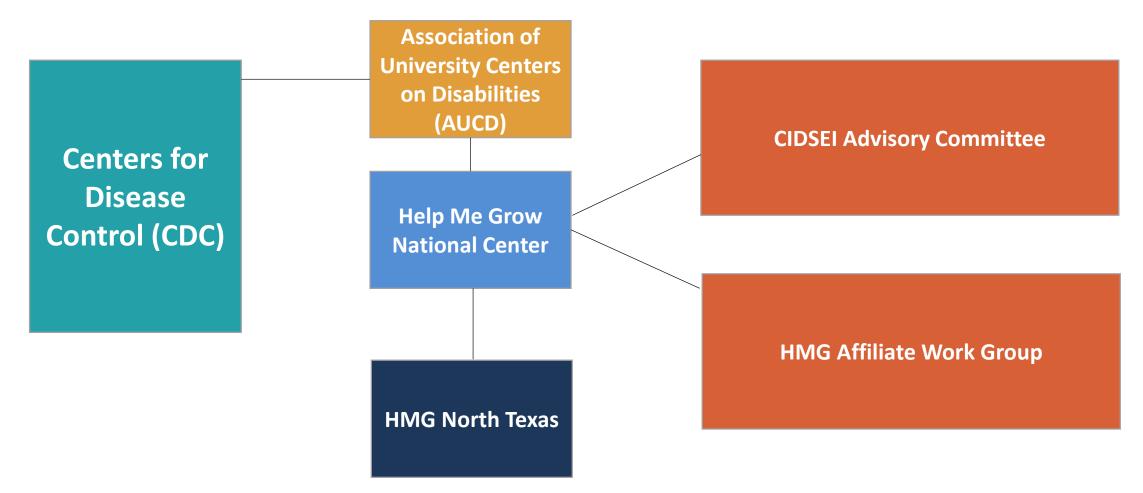
CDC, AUCD + HMG : An Integral Partnership

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Coordinated and Integrated Data Systems for Early Identification (CIDSEI)

- Explore and enhance state and territory capacity to improve the collection, management, interpretation, and dissemination of data related to developmental advancement and early identification of young children with developmental delays or disabilities
- Outgrowth of the CDC's Act Early Response to COVID-19, a project of the Learn the Signs. Act Early program
- Based on 4 steps of early identification:
 - 1. Parent-engaged developmental monitoring
 - 2. Screening
 - 3. Referral
 - 4. Receipt of services
- Timeline: November 2021-December 2022

Project Partners



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Phases 1 and 2

- Phase 1: Landscape Scan
 - Review of existing literature, work plans, needs assessments, resources, etc.
 - Findings:
 - Lack of data, program requirements, and data coordination around developmental monitoring
 - Lack of data systems in general, including coordinated and integrated data
- Phase 2: Key Informant Interviews
 - Key informant interviews with early childhood systems leaders across the world
 - Findings:
 - Lack of clarity around developmental monitoring as a distinct and important component of early identification
 - No universal strategies to employ monitoring activities, nor standard metric for measurement

Redefining the Final Product

- Could not share a toolkit for implementing a CIDSEI, because there are no current examples that could be replicated
- Need for a clarification of what family-engaged developmental monitoring (FEDM) is, what it looks like, and why it's important



A Roadmap for Advancing Family-Engaged Developmental Monitoring

Highlights

- The *Roadmap* introduces and describes family-engaged developmental monitoring (FEDM) as a key component of a framework for children's healthy development and family wellbeing
- Evidence-informed:
 - Literature
 - Phases 1 & 2 of the project
 - CIDSEI HMG Affiliate Work Group and CIDSEI Advisory Committee
- Key definitions and concepts delineated
- Program and Systems-level Self-Assessments

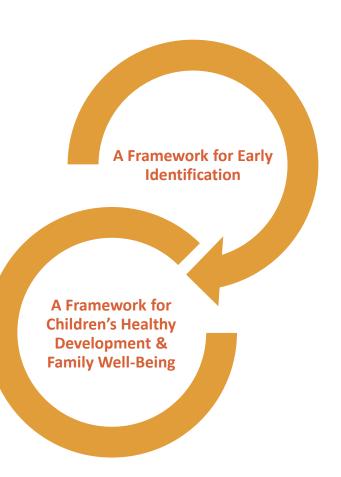
Implications

- Anticipated release: October 31, 2022
- What this Roadmap means for systems building
 - The Roadmap reflects the philosophy of HMG by affirming a family-driven, asset-based approach that recognizes what is going well and identifying families' priorities for their children
 - Can be used to ensure shared understanding of terminology, concepts and purpose
 - Self-assessments can be used internally for HMG (i.e. for CAP) as well as at the systems level to guide work

The Framework for Children's Healthy Development and Wellbeing

Early Identification Process

- Broader conceptualization of the process
- Asset-based approach with overall goal of promoting positive outcomes
- Recognizes families as leaders in their child's development



A Framework for Children's Healthy Development & Family Well-Being

- Framework describes the process needed to support child and family wellbeing, inclusive of early identification
- Inclusive of ongoing monitoring of young children who are not in need of early intervention but have identified risk factors for developmental delay
- Includes developmental promotion (re: education/interaction) activities as a discrete component
- Universal strategies:
 - Developmental promotion (ongoing)
 - FEDM (ongoing)
 - Screening (at recommended ages)
- Targeted strategies:
 - Referral to services
 - Receipt of services



Focusing on Family-Engaged Developmental Monitoring (FEDM)

- An intentional partnership of families and providers combining their knowledge to recognize child's developmental milestones and identify opportunities for support and education
- From birth and ongoing
- Inclusive of social drivers of health
- Supports a holistic understanding of the child's development and family conditions and provides increased opportunities for early identification

The 3 Attributes of FEDM



Holistic picture of child's development

Development is discussed longitudinally

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Family and Provider Strategies

FEDM Attributes	Family Strategies	Provider Strategies
Families are regarded as the expert on their child's development	 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 	 Providers solicit concerns routinely Providers ask family opinion of their child's growth Providers identify parent priorities – for growth and support needs
Information is compiled to produce a holistic picture of the child's context	 Families learn about factors that support or hinder development Families gather perspective from multiple adults or programs who interact with their children 	 Providers gather information about family strengths, risk factors, etc. Providers ask about other program/provider insights (from families or directly from other providers)
Development is discussed longitudinally	 Families note and reflect on their child's development over time (tools can help!) Families share how long any risk factors or concerns have been present Families revisit questions or progress with the same provider 	 Providers ask families how the child's development or their own concerns have changed over time Providers re-engage with the family to revisit questions, concerns, or developmental progress

FEDM: An Approach to Advancing Equity

- Practicing FEDM can support shifting the power dynamic back into the hands of families
- Developmental screening and evaluation may not be the best method of early identification for all families, due to historical institutionalized and structural racism
- FEDM is more accessible than components like screening, lending itself to broad utilization and acting as a strategy for targeted universalism

National Center on Birth Defects and Developmental Disabilities

Help Me Grow National Forum

September 22, 2022

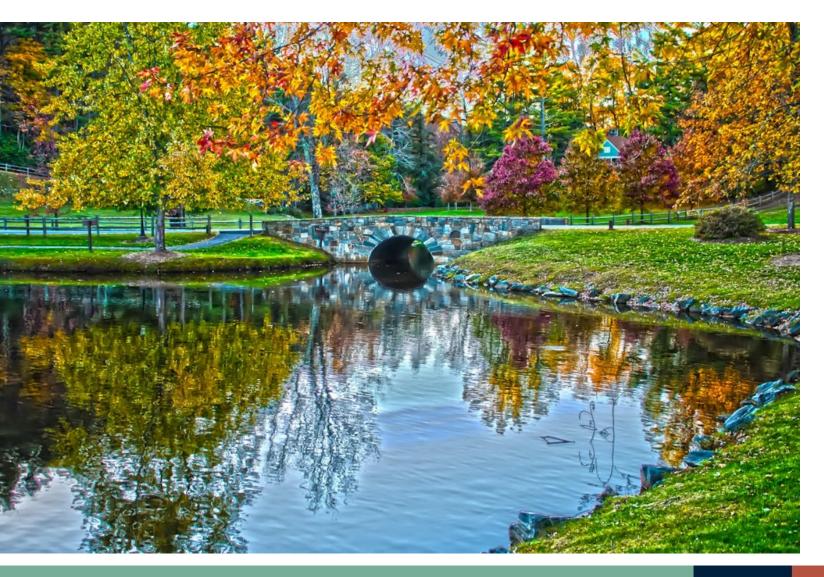
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Thoughts and Reflections



- Partnership
- Responsive
- Clarifying
- Inclusive

CDC's Learn the Signs. Act Early.

Key resources to facilitate family-engaged developmental monitoring



Thank you! KKGreen@cdc.gov

For more information, contact CDC 1-800-CDC-INFO (232-4636) TTY: 1-888-232-6348 www.cdc.gov

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.





Panel

Our Panelists



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Dr. Cynthia Tate, BUILD Initiative



Barbara Leavitt VP, Community Impact United Way of Central and Southern Utah

A Vision for the Future

The Ultimate Destination: Shared Values, Ideas and Actions in Early Childhood Systems

- Families are leaders in their child's development
- All providers that interact with families with young children engage in FEDM
- Social drivers of health and protective factors play an integral role in developmental outcomes, as well as all other components children's healthy development and family wellbeing
- Data from FEDM can support children and their families on the individual level, as well as inform population level data and system improvement
- Supported by this data, investments should be made to ensure that early childhood systems provide culturally appropriate support (education, tools, activities, services) to families to promote positive developmental outcomes



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