

# Coordinated and Integrated Data Systems for Early Identification

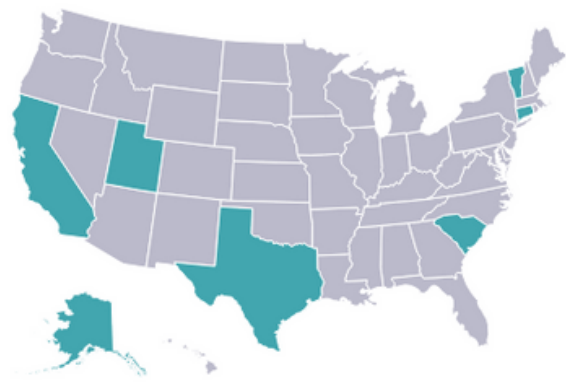
## HELP ME GROW AFFILIATE WORK GROUP

The Help Me Grow (HMG) National Center hosted the HMG Coordinated and Integrated Data Systems for Early Identification (CIDSEI) Affiliate Work Group from May to August 2022. This Work Group explored the necessary tools and resources needed to help develop a shared understanding of family-engaged developmental monitoring (FEDM) and the extent to which FEDM was valuable, resonant, and promotive to existing early childhood system-building efforts and HMG goals. The Work Group included eight HMG systems from across the HMG National Affiliate Network and was supported by the HMG National Center, the Association of University Centers on Disabilities (AUCD), and HMG Implementation Experts: Stephanie Walchenbach, Lynn Pullano, and Adam Hardy.

The experience and expertise of HMG affiliates was critically formative to the findings and outcomes of the CIDSEI project and the resulting Roadmap for Family-Engaged Developmental Monitoring.

Participants in the HMG CIDSEI Work Group were Alaska; Connecticut; District of Columbia; North Texas, TX; Orange County, CA; Sacramento, CA; South Carolina; Utah; and Vermont.

### HMG Systems that Participated in the CIDSEI Work Group



## The HMG Affiliate Work Group Experience

*Over the course of five Work Group sessions, HMG systems:*

- Participated in an ongoing data collection activity that explored the extent to which HMG data systems captured existing metrics and processes related to each element of early identification.
- Identified a variety of potential benefits to shifting the current language and terminology used in regard to early identification.
- Indicated a need for an overarching framework for child development that includes addressing social drivers of health and other contextual factors that impact child development.
- Recognized the valuable ability of the CIDSEI Roadmap and FEDM to:
  - Drive equitable best practices,
  - Raise awareness of HMG goals to partners and funders, and
  - Highlight the mechanisms utilized by HMG systems to ensure the needs of an entire family unit are met.
- Identified a need to ensure the family perspective is collected and captured in a broader data collection and analysis approach.
- Identified the need for and utility of program and system-level self-assessments as part of the Roadmap.

*Participants listed the following as most valuable takeaways from the HMG CIDSEI Work Group:*

1. Delineating the difference between developmental promotion and developmental monitoring.
2. Aligning with and advancing existing work by HMG National and the Affiliate Network.
3. Identifying future opportunities to further explore how FEDM can be measured and connected to other family and child-level data often associated with early identifications such as screening, referral, and linkage.

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### What HMG Affiliates Had to Say

What are three major takeaways from the work group sessions, the CIDSEI project, or FEDM Roadmap?

Strengths-based approach, appreciated the Work Group's work to clarify between general promotion of Act Early tools and active use of the materials with families (e.g. family-engaged developmental monitoring), and use of tools in addressing social determinants of health and equity.

-HMG Vermont

How will collecting information on the newly revised component, Family Engaged Developmental Monitoring, paint your overall HMG's data story?

Parents are the key factor missing from the story, we need both qualitative and quantitative data. Having a means of strengthening this information and then moving programs to serve families with better services.

-HMG Utah

In what ways will this Roadmap be helpful to you in conversations you are having with partners or funders?

Our state has a large cross-sector engagement with a group called the "Universal Developmental Screening Advisory Committee." While the name specifies developmental screening, there has been a lot of education done through this group to help differentiate between monitoring and screening. This has brought about a lot of promotion and educational opportunities for both providers and families. Because of the breadth of representation on this group, this document will help further the discussion around monitoring as a "component" and disseminate the information to a lot of players.

- HMG Alaska

What are the potential benefits to shifting the language and terminology related to the early identification framework?

This shift may bridge the gap between parents and providers. Often, families can find it difficult to understand or accept early delays. Changing the narrative can place a more positive attitude on the process.

-HMG District of Columbia