Project Overview

Coordinated and Integrated Data Systems for the Early Identification (CIDSEI) of Young Children with Developmental Delays or Disabilities

Effective coordination and integration of these data can improve detection of children with, and/or at risk for, autism spectrum disorder (ASD) and other developmental delay &/or disabilities (DD) and ensure timely receipt of services**.**

This Coordinated and Integrated Data Systems for Early Identification (CIDSEI) Project seeks to explore and enhance state and territory capacity to improve the collection, management, interpretation, and dissemination of data related to the four steps of early identification of young children with developmental delays or disabilities. The steps of early identification include:

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

This project will place special emphasis on parent-engaged developmental monitoring (step 1 of early identification). It is critically important to capture data on existing proactive, upstream efforts to engage parents and elicit their input and concerns related to their children's development. It is also important to ensure those data are shared and analyzed at a system-level along with the rest of the data more commonly and extensively documented across early childhood data systems (steps 2 through 4).

Select examples of proactive, upstream efforts to engage parents and elicit their input and concerns related to their children's development include:

1. Asking parents or caregivers about the milestones their child is achieving.
2. Asking parents or caregivers if they have concerns related to their child's development.
3. Noting and checking-in on known risk factors for delays.

This project is funded by the Centers for Disease Control and Prevention (CDC) and is administered through a cooperative agreement with AUCD.

The goal of this project is to identify:

- Challenges and barriers for data collection to determine what is required in states and territories for a CIDSEI,

- Which states are implementing components of a CIDSEI well

- Develop, assess, and share materials and resources encapsulated within a toolkit to facilitate data sharing and information exchange across early childhood programs/systems.
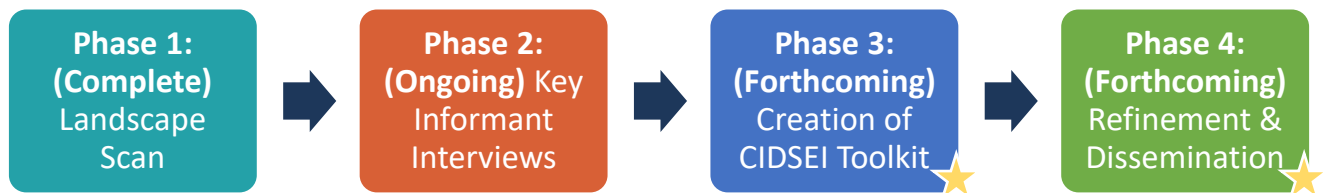
Project Partners

- **HMG:** The Help Me Grow National Center provides ongoing technical assistance to support the National Affiliate Network to diffuse the Help Me Grow Model and diffuse innovate system enhancements.
- **AUCD:** The Association of University Centers on Disabilities (AUCD) is a membership organization that supports and promotes a national network of university-based interdisciplinary programs.
- **HMG North Texas:** The HMG National Center has engaged a HMG implementer, HMG North Texas, as HMG affiliate who will inform the work with local system building expertise. HMG North Texas was established in 2019 and is housed within My Health My Resources of Tarrant County.

CIDSEI National Advisory Council

A national advisory council has been convened to inform this effort with representation from national organizations as well as federal agencies. The advisory council meet quarterly over the course of the project period. View CIDSEI National Advisory Council Members here

CIDSEI Project Timeline

Phase 1: (Complete) Landscape Scan → **Phase 2: (Ongoing)** Key Informant Interviews → **Phase 3: (Forthcoming)** Creation of CIDSEI Toolkit → **Phase 4: (Forthcoming)** Refinement & Dissemination

Phase 1: (Complete) Landscape Scan:

This landscape scan consists of best practices and barriers to integrated data systems designed to collect, manage, interpret and disseminate data related to early detection, referral, and linkage.

CIDSEI Landscape Scan

Phase 2: Key Informant Interviews:

Our project team will analyze and synthesize information obtained from key informant discussion groups and interviews related to the identified challenges, barriers and facilitators related to data collection on the four steps of early identification. Information from the landscape scan and key informant interviews will help to inform the CIDSEI toolkit (Phase 3) which will serve as a resource to support data collection, management, interpretation, and dissemination between and across early childhood programs and systems.

Phase 3 & 4: Toolkit Development and Dissemination

In the final phases of this project, the project team will develop a CIDSEI toolkit designed to be utilized by states and systems interested in developing a, or strengthening an, existing data system for early identification. The HMG National Center will convene a work group of HMG systems to inform the development of the toolkit and create a set of recommendation for best practices to consider when implementation a component of the CIDSEI Toolkit.