



Coordinated Integrated Data Systems for Early Identification

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

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Project Overview

The purpose of this project is to address system coordination and enhance the ability to track and monitor children with, and/or who are at risk for, autism spectrum disorder (ASD) and other developmental disabilities (DD). A coordinated and integrated data system for early identification (CIDSEI) would allow for data collection, management, interpretation, and dissemination between and across multiple early childhood programs and systems to ensure children and families are successful in accessing the services that they are referred to. The CIDSEI project will develop, implement, and evaluate activities to support states and territories to improve the collection, management, interpretation, and dissemination of data to guide their decision-making related to the four steps of early identification of young children with developmental delays or disabilities.

The Four 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 effort is supported with funding from the Centers for Disease Control and Prevention (cooperative agreement 6 NU38OT000280-02-02) and administered through a cooperative agreement with the Association of University Centers on Disabilities (AUCD). AUCD has subcontracted the Help Me Grow National Center who will leverage the HMG National Affiliate Network and HMG Implementation Experts to support the exploration, development, and implementation of this project.

The purpose of this project is to address:

1. system coordination and enhance the ability to track and monitor children with, and/or at risk for, autism spectrum disorder (ASD) and other developmental delay &/or disabilities (DD)
2. the need for system coordination for tracking and monitoring children is to ensure their receipt of services and to make the processes effective and efficient to prevent unsuccessful linkage to supports and services or loss to follow up.

Our Objective

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.

The intent of the CIDSEI toolkit is to support the development of data systems across multiple states and territories and aid in the tracking and monitoring of young children with possible developmental delays or autism to ensure children’s receipt of vital services to enhance their development.

Landscape Scan Methodology

The need for this proposed work is to better understand what is required for a CIDSEI within state/territorial early childhood systems and to identify the necessary tools and resources for the development (or refinement) of a coordinated and integrated data system. To assess current best practices, challenges, and existing resources dedicated to this topic, the Help Me Grow National Center conducted a thorough audit of existing trends, data, and measurement approaches (inclusive of identifying existing HMG affiliates with integrated technology platforms that allow for data collection, management, interpretation, and dissemination between and across early childhood programs and systems amongst its National Network. In addition to the HMG National Affiliate Network, the HMG National Center explored a wealth of resources prepared by national early childhood organizations, data management experts, and community and state level briefs specific to the exploration of integrated data systems.

This assessment was conducted using the following resources:

- Help Me Grow Annual Fidelity Assessment 2021
- Key informant interviews with HMG state leaders
- Identification of national organizations who mission ties closely with early child, data collection, developmental screening, data integration, etc.
- Review of existing brief and literature on topic of best practices and design of data systems
- Learn the Signs. Act Early. Ambassador work plans and materials
- AUCD COVID-19 Needs Assessment
- Review of existing resource related to Early Childhood Integrated Data Systems (ECIDS)
- Development screening and autism screening rate by state
- And many more



The Four Steps of Early Identification

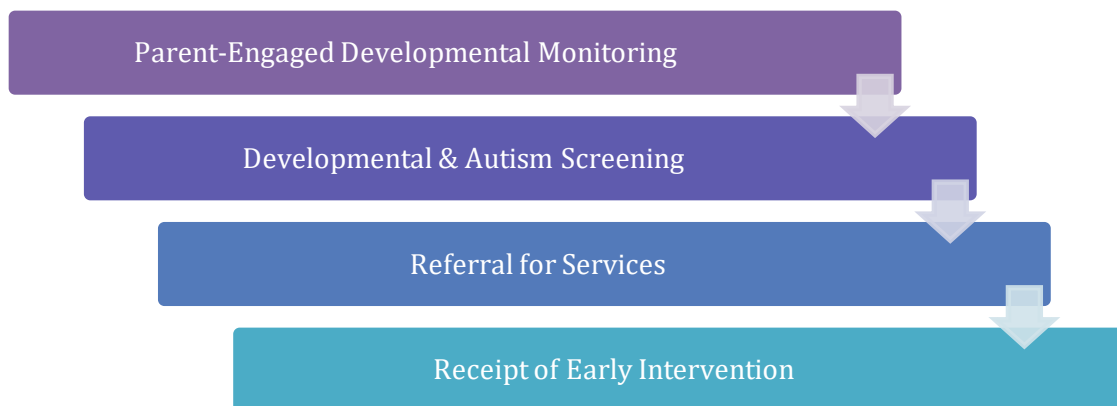
Step One – Parent-Engaged Developmental Monitoring (PEDM): Developmental monitoring refers to tracking a child’s development or behavioral status over time¹. PEDM more specifically refers to activities using materials and resources, such as those of the LTSAE program, to support parent’s knowledge of their child’s development and what to do if there is a concern.

Step Two – Developmental and Autism Screening: Developmental and autism (ASD) screening are more formal activities using a brief test of young childrens’ developmental-behavioral skills that can determine if a child should be referred for more comprehensive assessment¹. Screenings are conducted by trained early childhood providers using validated and normed instruments, most utilizing parent report.

Step Three – Referrals for Services: Referrals are concrete actions of early childhood personnel to get families connected to the next level of appropriate services¹. Referral for services occurs after a child fails a screening or if there continues to be concerns for the child’s development and well-being. Referrals facilitate access to Part C and Part B/619 evaluation and services, early care and education, mental health services, basic need resources, and community-based learning opportunities.

Step Four – Receipt of Early Intervention Services: In step-four a child has qualified for early intervention services under Part C or Part B/619 of the Individuals with Disabilities Education Act. These programs are accountable to that federal mandate’s timelines and protocols. System-level considerations include service accessibility, availability, and alignment with child or family needs-

Figure 1.0 The Centers for Disease Control and Prevention’s “Learn the Signs. Act Early.” Program’s Early Identification Model



¹ Bricker, D., Macy, M., Squires, J., & Marks, K. (2013). *Developmental screening in your community: An integrated approach for connecting children with services*. Paul H. Brookes Publishing.

Which States are Exploring Integration Amongst the Four Steps of Early Identification?

With funding made available by the CDC, states implementing the *Learn the Signs. Act Early.* program have been given the opportunity through federal funding dedicated to COVID-19 Response to focus on the necessary support to families as they navigate the four steps of early intervention.

The Act Early Response to COVID-19 Project

The Act Early Response to COVID-19 Project was developed to lessen the negative effects of the COVID-19 pandemic on the early identification of developmental delays and disabilities. The project also aims to increase support for families with young children during this stressful time. It is funded through federal COVID-19 supplemental funding and administered through a cooperative agreement between CDC and AUCD. The project funds and supports Act Early Ambassador-led Response Teams, which are made up of representatives from different early childhood programs. These Response Teams collaborate to ensure continued early identification of young children with developmental delays and disabilities during the pandemic, and to support resiliency among children, families, and communities.

The Response Teams were tasked with developing work plans around four primary goals. The goals for the first year included (1) develop and coordinate an Act Early Ambassador-led (or co-led) state/territory team of partners from different early childhood programs, (2) engage the state/territorial team in conducting a needs assessment for early identification during the COVID-19 pandemic, (3) develop, implement, and evaluate a plan to address early identification in the state or territory, and (4) identify, implement, and evaluate strategies to support the resiliency of children, families, and communities in the face of the COVID-19 pandemic. For more detailed information about the activities implemented in year one you can review [The Act Early Response to COVID-19 Project: Year One At-a-Glance](#).

The AUCD and CDC used program evaluation data to organize the year one activities around three focus areas; (1) communication and dissemination, (2) training, and (3) policy changes. Examples of those activities can be found in *Appendix B*.

Year Two of the Act Early Response to COVID-19

The project was funded for a second year and currently 41 Response Teams continue their efforts to improve and ensure the early identification of young children continues. In year two of the project the CDC and AUCD amended the goals from year one by including a directive to develop, implement, and evaluate activities to prevent loss to follow-up for young children and their families as they traverse the early identification process. Several of the Response Teams are choosing to address loss to follow-up through the use of data. Examples of Response Teams whose work plans include a focus on data are provided in Table 1.0.

Table 1.0

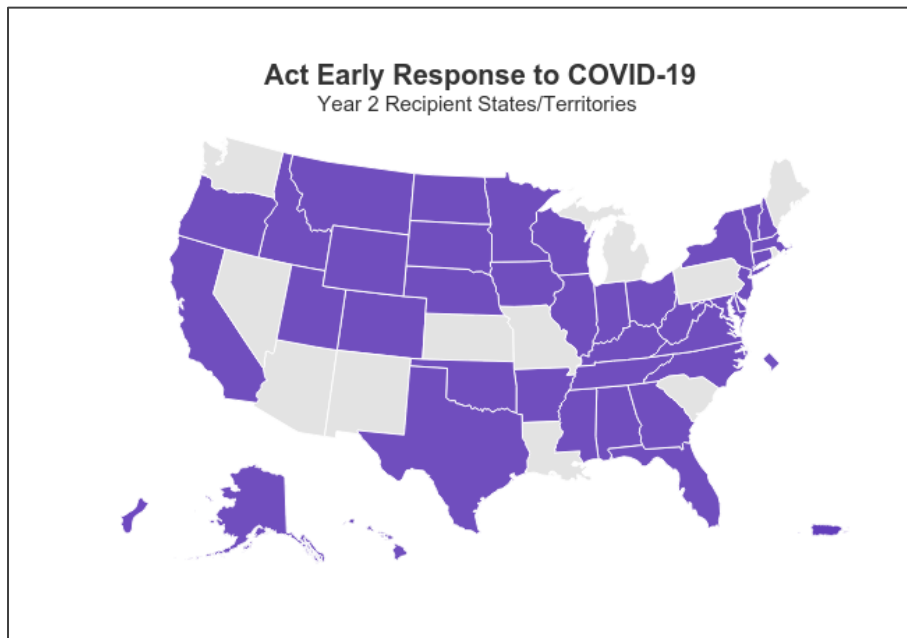
<p>North Dakota</p>	<p>North Dakota’s work plan is dedicated to decreasing the rate of families lost to follow up by collaborating with the Early Development Network (EDN) by designing and piloting a new Early Intervention referral/referral tracking app for use by families over the course of 2021-2022.</p>	<p>Indiana</p>	<p>Indiana plans to merge Part C and Part B/619 data systems and conduct analysis using Indiana University’s Statistical Consulting Center to assess the impact of this data merge.</p>
<p>Kentucky</p>	<p>Kentucky is working to hire a part time coordinator and develop the LTSAE HMG Developmental Surveillance Program with 10 pilot childcare centers who will be entered into the HMG data base. The childcare programs will receive training and TA to set up monitoring, screening, and referral processes. Referrals to EI will be tracked. Childcare programs are incentivized through points in the states QRIS.</p>	<p>Vermont</p>	<p>Over the course of 2022, Vermont plans to produce a brief report including the key needs and gaps in the state’s system and data-driven recommendations to align efforts across sectors for all four LTSAE steps and ensure that children are receiving the appropriate services.</p>
<p>Tennessee</p>	<p>Tennessee is working to determine broad patterns of referral, eligibility, and receipt of early intervention services by review of state level data from Part C program (when available from agency). The state has new metrics for parent satisfaction of various steps in the process to help inform outcomes and judge loss to follow-up.</p>	<p>Wyoming</p>	<p>Wyoming is developing a coordinated intake system that will be embedded into the current home visiting data collection system in their state to address the four steps of early identification. The state also has an existing Ages and Stages Questionnaire (ASQ) online portal system and HMG data systems that will inform this work.</p>
<p>North Carolina</p>	<p>North Carolina plans to survey of their local Interagency Coordinating Councils (LICCC) on the 4 steps of early identification. They will use the data to analyze the impact of the pandemic on referrals and equity issues</p>	<p>Georgia</p>	<p>In 2021, Georgia focused on the planning of a statewide early childhood data system for early identification. Over the course of 2022, the state will utilize a policy and research group dedicated to working with early childhood programs around data sharing agreements and barriers to policy changes.</p>
<p>Nebraska</p>	<p>Nebraska is working to support families across the steps and decrease loss to follow up, the team will collaborate with Early Development Network (EDN) to design and pilot a new Early Intervention referral/referral tracking app for use by families.</p>	<p>Idaho</p>	<p>Plans to conducting a pilot program with Part C, Child Find, and childcare center to make recommendations about next steps on how best to integrate data around the four steps to early identification</p>

The Act Early Response to COVID-19 Needs Assessment

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 COVID-19 pandemic on early identification efforts. The 43 state and territory Response Teams participated in the needs assessment (N = 397). Response Teams included state and territory’s Act Early Ambassadors along with multi-sector program and system administrators. Programs and systems included, but are not limited to, are Title V, Help Me Grow, Healthcare, IDEA, ECCS, Early Care and Education, Child Welfare, and WIC.

One finding from the needs assessment was related to the Response Teams ability to monitor, using data, their early identification efforts to ensure young children and their families were in receipt of services. Respondents reported varied barriers including a lack of a coordinated system, the inability to share data across programs and systems (i.e., integrated data), failure to collect data, a lack of existing data, inability to access data, and a lack of a centralized data repository.

The following section provides specific examples of responses from the varied programs and system administrators participating in the needs assessment. Included with each example are the state or territory abbreviation and the program or system they are representing. One finding from the needs assessment demonstrated that in addition to the named programs and systems the majority of respondents fell into an “other” category. The “other” category included members from higher education, family advocacy, and local, state, and national non-profits. An overview of Examples of Responses Related to State and Territory Data Needs for Each of the Four Steps of Early Identification can be found in Appendix B.



What Respondents of the Needs Assessment Told Us

Step One - Parent-Engaged Developmental Monitoring (PEDM): The majority of responses were related to questions about PEDM activities. These questions included family’s access to those materials and activities, family’s beliefs about activities, and child outcomes from PEDM activities (see *Appendix C.*) Noted needs related to data for PEDM (*Appendix D.*) included a lack of data on this step, a lack of program requirements for this step, and a lack of coordination around data in general. Finally, there were also multiple responses about the overall need for an early identification data system. These responses included a lack of data systems in general, a lack of coordinated data, and a lack of integrated or shared data (see *Appendix E.*)

Step Two - Developmental and Autism Screening: Responses for step two included needs related to systemic issues. Issues included not having access to screening data, lack of data sharing, concerns about duplication of screening, concerns about disparities for which children who do or do not receive screening, timeliness of screening, and administrative barriers with Medicaid.

Step Three - Referral for Services: Responses for step three centered on what happens after a referral and a lack of ability to determine if there is follow through or follow up, highlighting the need to “close the loop” on the process of early identification. Concerns were also noted here related to gaps and disparities in referral services, the inability to know if they exist, and who is impacted. Additionally, there were basic concerns about just needing to know the number of children who are being referred.

Step Four – Receipt of Early Intervention Services: Responses for step four indicated that concerns ranged from needing to know the number of children in both Part C and Part B/619 and who is missing to those related to the quality of services, including child outcomes, and how the pandemic and the move to remote services impacted children and families. In addition, responses also demonstrated a need to know about children leaving Part C, or who aged out prior to Part B/619, and what the long term outcome was, such as needing special education services at an older age.

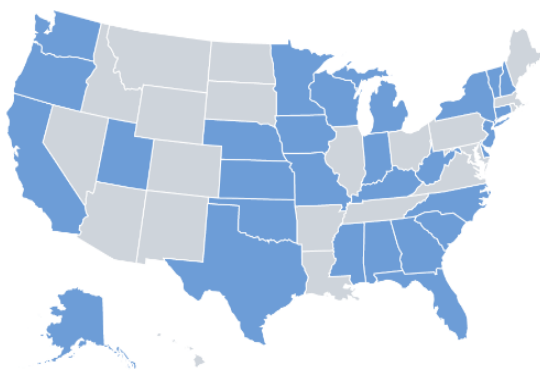
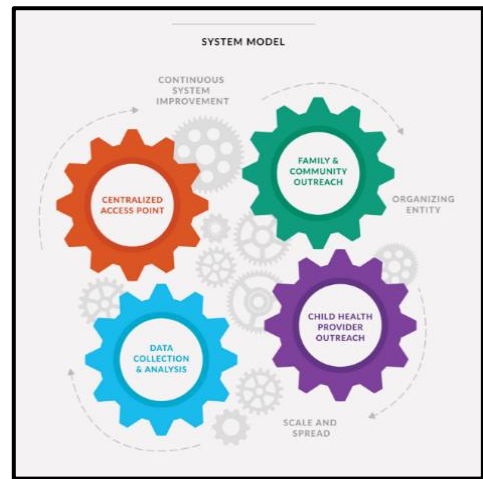


The Help Me Grow Model & National Affiliate Network

Help Me Grow (HMG) is not a stand-alone program, but rather a system model that leverages existing resources in order to develop and enhance a comprehensive approach to early childhood system building in any given community. Successful implementation of the HMG Model requires communities to identify existing resources, think creatively about how to make the most of existing opportunities, and build a coalition to work collaboratively toward a shared agenda.

Four cooperative and interdependent core components characterize the HMG Model:

1. A **Centralized Access Point** assists families and professionals in connecting children to the grid of community resources that help them thrive.
2. **Family & Community Outreach** builds parent and community-based organization understanding of healthy child development, supportive services that are available to families in the community, and how both are important to improving children's outcomes.
3. When providers identify potential concerns early on, they can be easier to address. **Child Health Care Provider Outreach** supports early detection and intervention efforts and connects medical providers to the grid of community resources to best support families.
4. To make sure the resource grid is working effectively, **Data Collection & Analysis** supports evaluation, helps identify systemic gaps, bolsters advocacy efforts, and guides quality improvement.



The HMG Model also depends on three Structural Requirements to provide the foundation for building and managing the Core Components of a HMG system effectively over time. Implementation relies on an Organizing Entity to provide support, oversight, continuity, and facilitation of collective impact efforts. Critical strategies for Scale and Spread ensure that systems optimally serve to meet the needs of all children and families. The efficacy and durability of the Help Me Grow Model also hinges on Continuous System Improvement, or constant efforts to enhance, refine, and innovate.

HMG was first piloted in Hartford, Connecticut in 1997. Since that initial implementation, a growing number of states and communities have replicated the HMG Model as a strategy to support early detection of developmental or behavioral concerns, as well as the referral and linkage of those children to appropriate medical and community services. Currently, there are 118 HMG systems operating within 28 states and Washington D.C.²

The Help Me Grow Model & the Four Steps of Early Identification

Help Me Grow is a systems level approach to optimizing the health and wellbeing of children. HMG is uniquely positioned to support families through the four steps of early identification. Early childhood service providers plug into the HMG system creating a seamless network of supports for families with young children. Within many communities, HMG serves as the triage point to Part C, Part B, Home Visiting, Parenting Support, school readiness and other early childhood programs. HMG also serves as a care coordination arm for child health providers and often provides developmental screening and monitoring outside of the well child visit. A closer look the key elements of the HMG Model as they relate to the four steps of early identification can be found in Table 2.0.

Table 2.0

<p>Step 1: Parent Engaged Developmental Monitoring</p>	<p>Targeted outreach to families through marketing and public awareness campaigns, family engagement events, and strategic partnerships with existing parent support and advocacy groups increases knowledge and understanding of children’s optimal healthy development. This outreach engages families as critical partners in supporting the wellness of their young children. These family outreach strategies also foster awareness of the HMG Centralized Access Point, which provides families of young children with support in navigating the landscape of early childhood programs, thus transferring the onus of complex system navigation from the caregiver to trained and dedicated HMG Care Coordination staff.</p>	<p>Step 2: Developmental and Autism Screening</p>	<p>A variety of screening efforts are conducted within the HMG Centralized Access Point and through HMG led or coordinated events dedicated to promoting developmental milestones and educating families on their child's healthy development. Screening results are shared back with families and HMG Care Coordinators support those whose results may indicate need for monitoring or referral to services. Families receive targeted and valuable referrals, and HMG Centralized Access Point staff systematically follow up with families to help them overcome barriers to accessing needed services, provide ongoing support, and ensure needs are met.</p>
<p>Step 3: Referral to Services</p>	<p>The HMG Centralized Access Point serves as a care coordination arm for busy pediatric primary care practices when providers identify concerns and, in so doing, HMG partners with providers to ensure effective linkage to appropriate programs and services. In addition to serving as this extension of support to child health providers, HMG systems mirror similar approaches to community partners who conduct developmental monitoring and screening with families with young children. Community partners leverage the Centralized Access Point for care coordination support and referrals for families in need.</p>	<p>Step 4: Follow up and Receipt of Early Intervention</p>	<p>The HMG Centralized Access Point systematically closes the loop with referring child health care providers and community-based service providers so families are optimally supported, communication is streamlined, redundancies are minimized, gaps are identified, and children receive what they need when they need it. Throughout each component, Data Collection and Analysis further bolsters the ability to close identified systemic gaps and strengthens the entire system as a whole.</p>

² HMG National Fidelity Assessment, 2021.

State Spotlight: Help Me Grow California

The State of California operates over 30 HMG systems on the county-level across the state. HMGs were built intentionally at the local level to directly support families and establish trust between HMG, community partners, and families. HMG systems are designed to educate families and caregivers on developmental milestones, improve developmental screening rates, and provide critical care coordination services in order to efficiently link families with young children to the supports they need related to their child’s health and development.³ HMG’s systemic approach to early identification, referral, linkage, and follow up supports California in responding to and serving children at risk for developmental delays and behavioral concerns.

There are numerous examples of HMG California counties integration of data and support to families, the HMG county-level systems below illustrate just three of the innovative ways in which California is doing this work:

- **HMG Inland Empire**, a system supporting families across two counties, piloted the integration of an electronic ASQ, electronic social determinants of health screen, and Wellness Map into Epic, the electronic medical record (EMR) platform used by the local medical center, Riverside University Health System, and a local Federally Qualified Health Center. HMG Inland Empire focuses on using zip code-specific data to populate the Wellness Map feature with community-based resources for children and families identified as at-risk with one or more social determinants.
- **HMG Yolo County** offers universal mental health screening for both parents and kids ages 0-5. They also utilize evidence-based tools to identify parental or household risk factors that can undermine healthy development, such as the SEEK Parent Questionnaire and the Environmental Screening Questionnaire (ESQ).
- **HMG Fresno County** collaborates with their county’s largest school district and Office of Education to offer Mid-Level Developmental Assessments (MLDA). MLDA’s are a mechanism to provide assessment between an initial screening that from a provider or physician and an in-depth evaluation by a specialist. MLDA’s provide sufficient information to expedite connection to services and wraparound supports.

³ First 5 Center for Children’s Policy. (2020, May). *California’s Early Identification and Intervention System and the Role of Help Me Grow*.

Early Childhood Partners: Roles within the Four Steps of Early Identification

The spectrum of early childhood programs and providers who work closely with the four steps of early identification is extensive. Some providers span all four steps and work with families as they move through each. A majority of providers are well positioned to share educational materials and support parents in monitoring their child’s developmental health. Some shine when it comes to one or two steps of early identification, but rarely are they providing all four steps. Nevertheless, many track data respective to their individual roles within the four steps, in their own databases. Given the nature of the work of each of these service providers, there can be challenges when it comes to coordination and integration of data related to each of the steps of early identification across each of their existing data systems.

Early Childhood Partners utilizing at least step of Early Identification

- Women, Infants, & Children
- Head Start/ Early Head Start
- Part C
- Part B/ 619
- Publically Funded Preschool
- Help Me Grow
- Learn the Signs. Act Early. Ambassadors
- Home Visiting
- Title V
- Kindergarten Readiness Programs
- Healthy Steps
- Family Connects
- Pediatricians and Primary Care Providers
- Other Medical Providers
- Child Care Providers
- Community Health Workers

Coordination & Integration of Data

Data systems reflecting children in Pre-Kindergarten through twelfth grade have long served as means to view children’s progress, challenges, and supports. Prior to Pre-K, children and families often interact with several types of supports and services specific to potentially identify and address any existing needs before a child enters school such as home visiting, Women, Infants & Children, and childcare. These organizations often collect data on the child and family but do not share those data with other agencies outside of their own. The absence of strategic data sharing can hinder a community or state’s ability to: support families who are accessing multiple services, understand the breadth of support needed on a community and state level, advocate for early childhood funding and policy, and many others. To better serve children and families, integrated data systems are necessary to collect, monitor, interpret, and disseminate data that encompasses the broad spectrum of services that children are exposed to prior to starting Kindergarten.

Prior to the creation of Early Childhood Integrated Data Systems (ECIDS), there were limited examples of data systems designed to collect, monitor, and disseminate data specific to the supports with which children interact from birth through five years of age.² An ECIDS has the ability to bridge data from a variety of agencies, services, and organizations that families with young children so often interact with over the course of those early years. This is of particular importance as each of those agencies and services are designed to capture their own data, often dictated by their funding, program requirements, and goals.² There are a multitude of data points collected

from the time a child enters preschool through graduation and ultimately their entrance into the workforce. State Longitudinal Data System (SLDS) have often been used as a means to store and examine these data for community level support, funding, and policy.⁴ The primary education data system creates a strong base of demographic, educational, and medical data that is tied to unique child identifiers and is stored and accessible for a long period of time. While an ECIDS and SLDS operate separate from one another, the data can be linked to create a fuller picture of at the community and/or state level of child from birth through the workforce.

There are two significant approaches to data integration, vertical and horizontal integration, amongst early childhood (birth through 5 years of age) data and Kindergarten through twelfth grade and workforce data systems. Horizontal data integration highlights the linking of existing data across child serving programs and providers within a similar sector (i.e. early childhood) whose data systems often operate in silo from one another.

Benefits of linking data horizontally include:

1. The ability to utilize aggregate data to advocate for funding and policy opportunities
2. The ability to enhance coordination amongst program and providers
3. The ability to understand which children are being served, by who, and how often

A vertical approach to data integration involves the linking of data from programs and providers serving children birth to five years of age to those serving children preschool age and older.⁴ Challenges cited with vertical integration include those related to matching unique child identifiers, alignment of data practices to assure data quality, and the difficulties of merging data that reside in several separate systems.⁵

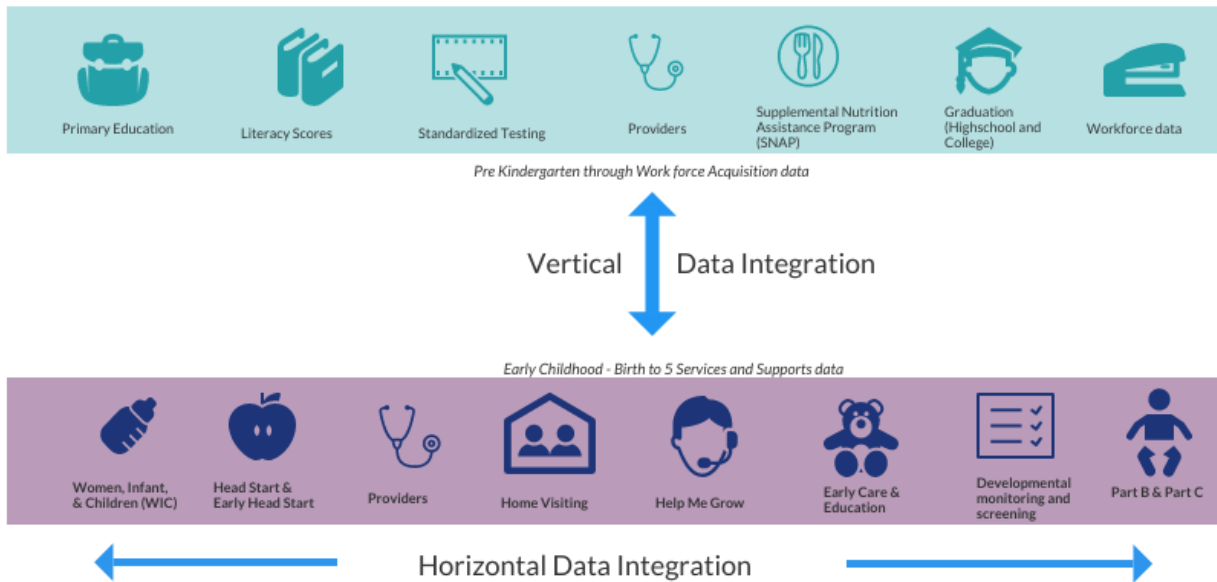
Benefits of linking data vertically include:

1. The ability to utilize child level data to inform and forecast supports and services needed as children enter primary school
2. The ability to utilize community or state level data to assess impacts of early child support and services later in life
3. The ability for early childhood programs and providers to draw from such impacts to advocate for funding and program enhancement

⁴Department of Health and Human Services & Department of Education of the United States of America. (2016, November). *The Integration of Early Childhood Data: State Profiles and a Report from the U.S. Department of Health and Human Services and the U.S. Department of Education*. [The Integration of Early Childhood Data \(PDF\) \(ed.gov\)](#)

⁵ BUILD Initiative & Child Trends, Early Childhood Data Collaborative. (2015). *Rising to the Challenge: Building Effective Systems for Young Children and Families, a BUILD E-Book* (Chapter 7: Stacking the Blocks: A Look at Integrated Data Strategies). BUILD Initiative.

Integrating data horizontally across early childhood agencies is the recommended first priority before integrating vertically with a system like an SLDS to understand programmatic impact and return on investment in the long term.⁴ The figure below depicts an example of horizontal data integration amongst programs and providers serving children birth through 5 years that can then inform a SLDS such as the primary school education data system that tracks and monitors child level Pre-Kindergarten through graduation and beyond.



Foundational Elements of Integrated Data Systems

A 2019 report by Nemours, one of the largest integrated children’s health systems in the United States, outlines the foundational elements to assess readiness when it comes to an integrated data system for early childhood. The three foundational elements include: Building Trust, Establishing Champions, and Aligning Goals.⁶

Trust: Building Trust amongst community partners and leaders is an integral element in the success of an integrated data system. Early childhood provider and program data systems hold sensitive information related to the children and families they serve. An integrated and comprehensive early childhood system that includes data from families with young children from birth, from all early childhood programs must place significant importance on trust. In addition to the establishment of trust amongst partners who would plan to share or disseminate the data, families themselves require a level of trust and transparency related to who will have access to their children’s information and how it will be used to inform both efforts that will support them directly and on a community aggregated level.⁶

⁶ Nemours Children’s Health System, Hewitt, A., Gratale, D., Counts, N., Hogan, L., & Cheng, D. (2019, October). *Data Sharing Across Child-Serving Sectors: Key Lessons and Resources*. Nemours Child Health System.

Establishing Champions: It is critical to identify and engage partners with position, power, expertise, and the ability to mobilize the funding necessary to create and maintain an integrated data system. Communities should consider who is already a leader and innovator in this work within the community and/or state, as well as those who could benefit from participating in the sharing and/or dissemination of data. Nemours highlights the success of integrated data systems that are inclusive of multiple sectors and partners who are willing to share and link their existing data with one another.⁶

Goal Alignment and Shared Management: Goal alignment and shared measurement should be pursued by establishing trust amongst key champions and partners with a shared understanding of how each sector contributes to success.⁶ These relationships and ongoing communication are essential for choosing the best model of data integration for each partnership. Partners entering into an integrated system together should consider what each individual partner wants and needs from the data system in order to be successful.

What are the Benefits of Linking Data across Early Childhood Systems?

1. Continuous quality improvement opportunities
2. Program enhancement
3. Inform policy efforts
4. Advocate for funding and support for early childhood services and programs
5. Reduce instances of the same child being counted multiple times by multiple services (more accurate data)
6. Identify which children and families are not being served
7. Assess service quality as it related to childhood outcomes
8. Improve coordination and service delivery
9. Ability to integrate vertically with longitudinal data systems and assess long term impacts of programmatic supports for children served

Best Practices of Early Childhood Data Integration

The development of an integrated data system takes thoughtful preparation and significant effort to engage motivated partners, build meaningful data sharing agreements, and align goals amongst collaborators and partners. Table 3.0 describes a number of best practices that have supported states to successfully move closer to developing a functioning integrated data system that improves the lives and outcomes of young children.

Table 3.0

<p>Identify Data Needs</p>	<p>Identifying community, state, and programmatic needs early on in the planning of an integrated data system is essential. With mutual understanding of how the data collected could be disseminated can assist in planning, leveraging existing data structures, engaging partners, securing funding, and much more.</p>
<p>Assigning Unique Child Identifier (UID)</p>	<p>A UID allows a state to track progress of each child throughout their lifetime, across multiple data systems, programs, and sites within a state, which ultimately allows for improved coordination and provision of services and eliminates redundant data entry.</p>
<p>Leveraging Existing K-12 Data Systems</p>	<p>Leveraging existing K-12 data infrastructure allows states to design their early childhood data integration systems with the intention of alignment with both data governance bodies and technological platforms and ultimately allows for ease of data sharing vertically once the early childhood system is in place.</p>
<p>Engage Partners</p>	<p>Engaging partners and innovators who have expertise in this work within the community and/or state is important. Data integrators should engage these individuals early on in the planning process as well as those who could benefit from participating in the sharing and/or dissemination of data to create buy in and shared understanding.</p>
<p>Developing Data Sharing Agreements</p>	<p>Data sharing agreements specify which agencies and parties will have permission to access the data collected, what kinds of data they will be able to access, and for what purposes the data will be used. For many states, this step requires significant staff time and open lines of communication across agency contacts. This step is unique to each state and what works effectively in one state may not work well in another.</p>
<p>Clear, Concrete, and Achievable Goals</p>	<p>Designating and articulating clear, concrete, and achievable goals helps participating agencies and programs understand their short and long-term implementation strategies and also allows states to stay focused without becoming overwhelmed by obstacles or paralyzed by goals that may not seem possible to achieve.</p>
<p>Effective Communication</p>	<p>Effective communication strategies are an essential driver for overcoming challenges, advancing efforts, preventing potential misunderstandings, and helping participants visualize what the data system will and will not be able to do.</p>
<p>Technical Assistance</p>	<p>Ongoing technical assistance and training is essential in navigating challenges specific to data integration, data sharing agreements, security and privacy, and other technological issues. Technical assistance also provides a foundational knowledge base that can deliver assistance along the way.</p>
<p>IT and Legal Consultants</p>	<p>It is critical to ensure sufficient IT capacity possessing the necessary qualifications and competencies to build the data system, including contribution from a legal team early on in the process to help work through legal and policy considerations related to HIPAA and FERPA which can often serve as barriers to cross sector data sharing.</p>

State Spotlight: Illinois

The Chicago Department of Public Health (CDPH) and Chicago Public Schools (CPS) worked together to improve childhood education and wellness. Illinois is a strong example of a state that utilized the best practices identified above such as effective communication, developing data sharing agreements, and recognizing the importance of partner engagement. The state identified partner data needs early on to achieve their respective goal. CPS and CDPH developed an umbrella data sharing agreement that would allow for the exchange of information for commonly used data without prior permission.⁵

The Illinois State Board of Education operates the Child Find Project funded by IDEA Part B, Preschool Discretionary funds to develop and disseminate public awareness materials to Local Education Agencies, Special Education Cooperatives, and the Child and Family Connections offices. One activity of the Project is to collect and share data on the number and location of developmental screenings in addition to both vision and hearing. Programs screening manually enter number and location of developmental screening tools used, type of reporting program/entity, type of referral and referral counts, on paper forms and faxed to The Child Find Project managed by a single Program Coordinator.

Recently Brookes Publishing hosted webinars highlighting the work of a Collaboration for Early Childhood, a collective impact agency in Oak Park, Illinois that designed a trainings and coaching plan to support the four steps with early childhood center-based programs, home-based early education programs, pediatric practices, home visiting programs and public libraries to promote screening, effective communication, and referrals using ASQ online. In addition to supporting Kindergarten Readiness and early identification of needs within their community, the Collaboration for Early Childhood serves as the single point of contact for connecting and guiding families to quality preschool, home visiting, and developmental supports for families.

Importance of Partner Engagement

Engaging key partners early on, as well as developing a process for them to transparently identify their data needs and potential use cases, is an integral step that sets the tone for the entirety of the project. In addition to thinking through how best to use the data, states must consider how best to communicate the value of the integrated data to end users. Once the priorities of the end users are determined, states can utilize this knowledge and feedback in their planning and development of the system so all partners' needs are met.⁵

Numerous federal funding awards have afforded states the opportunity for comprehensive planning and coalition building around data integration, including but not limited to Preschool Development Grant Birth to Five (PDG B-5), Race to the Top, and Early Childhood Comprehensive Systems (ECCS). These investments have enabled grantees to fund statewide data advisory councils, the development of integrated data infrastructures, and establish collaborative technical and governance practices. The scale of these funding streams and grantee

cohorts have produced robust resource repositories and technical assistance. Next phases of this project can explore how state early intervention data integration groups are utilizing this array of existing assets.

Parents and caregivers are an important partner in the design and implementation of an integrated data system for early childhood. Early childhood data systems house sensitive information regarding the development and wellbeing of children. Designers and implementers of a state’s coordinated and integrated data system must prioritize and communicate the security of a child’s information both within the data system itself and once data is reported out from the system.

Additional considerations:

Variety: Each aspect of a cohesive developmental promotion and early intervention system touches its own constellation of partners. With its varying degrees of data formality, and the elements that range from policy to legal to service delivery to the family experience, engaging the relevant experts throughout is a tall order.

Continuity: Amidst a necessary diversity of players, it is valuable to have designated partners involved across aspects of the system, to promote alignment and communication across agencies and user types. Within a partner group, turnover in decision-making as well as support staff positions requires continual education and relationship building to prevent knowledge loss and maintain project funding and buy-in.

State Spotlight: Connecticut

Using Technology to Connect Families and Early Childhood Providers

The Connecticut Office of Early Childhood (OEC) offers a universal mobile app to families across the state with children 0-5 years of age and the programs that serve those families. Made possible through state legislation and Preschool Development Grant funding, the Sparkler app is free of cost to families and available in multiple languages.⁷ Families utilize the app to learn about developmental milestones, access age appropriate ASQs, track their child’s development, and connect with their child’s providers.⁸ Screening results reporting within the app are shared directly with CT’s OEC so parents can to connect directly with care coordinators specializing in early childhood through virtual coaching.⁷

⁷ State of Connecticut. (2021, October 21). Connecticut Launches New Statewide Tools to Help Parents Check in on Children’s Development, Access Expert Tips and Answers, and Support Healthy Early Development. [Press release]. <https://www.ctoec.org/wp-content/uploads/2021/10/Press-Release-OEC-and-Partners-Announce-Statewide-Launch-of-Sparkler.pdf>

⁸ Sparkler. (2021). *Sparkler Connecticut*. Sparkler Connecticut. Retrieved January 7, 2022, from <https://www.playsparkler.org/connecticut/>

For providers, the app is a mechanism to engage with families, monitor and screen children's developmental progress logged by the parents, and share activities and messages to their patient's families. ⁸ As of 2021, the app is available in over 70 communities statewide and utilized by a variety of early childhood providers such as:

- School districts and preschools
- Family-Resource Centers
- Community-based Organizations
- Family Child Care
- Home Visitors
- WIC
- DCF
- Help Me Grow
- Health Providers
- 211
- School Readiness Organizations

While the Sparkler app is not a data system, it is a wonderful example of a coordinated mechanism in which a number of early childhood providers are engaging with family-level data around developmental monitoring and screening. Through the Sparkler app, families are able to provide responses to a single Ages and Stages Questionnaire that can then be shared with all the providers with which their child interacts. As the Office of Early Childhood also oversees Part C, home visiting programs, and Help Me Grow, there is opportunity and intention to integrate data across these services. In addition, many state level partners, like the CT's Department of Families and Children are exploring the requirement of the app to be used by caseworkers. This is a great example of how a policy change can support aspects of early identification for children with risk factors and the created of a streamlined and supported early childhood system.

State Spotlight: Kansas

Kansas's PDG-funded state strategic planning process, All In For Kansas Kids, is yielding an aligned approach to more uniform ASQ use, infrastructure, and financing. This allows them to leverage existing screening efforts and expand participation at both the agency and community levels.

- Infrastructure: The state level workgroup identified 17 existing enterprise or pro-level accounts for ASQ Online, many of which shared a funding agency. Even with this number of enterprise systems in the state, communities and providers expressed availability and access barriers to screening. The PDG leadership group has expanded the existing Kansas Department of Education Enterprise Account to include 30 new Community ASQ Enterprise accounts connected by a hub and began implementing this statewide ASQ Online System in 2021.
- Use: The Kansas Department of Education launched the Kindergarten Snapshot – an ASQ-3 and ASQ SE: 2 administered screener at school entry in 2018, and have screened nearly 100,000 kids over the past three school years. In 2021, under All In For Kansas Kids, KDHE and KSDE entered into a collaborative agreement to add 30 Community ASQ Enterprise accounts managed by local Part C agencies, offering free ASQ online subscriptions and covering the per screen costs for 3 years.

- Financing: The cost of ASQ Online as well as ASQ-3 and ASQ: SE-2 kits (licenses) were a longstanding financial barrier to screening for community providers. By negotiating a bulk price with the ASQ's publisher, Kansas can now offer reduced-price kits to community providers joining the collective ASQ system.

What States are Linking Data across Early Childhood systems?

There are many examples of states exploring coordination and integration of early childhood data. The most recent resource detailing state by state examples of coordinated child level data is a survey conducted by Child Trends and the Early Childhood Data Collaborative in 2018. The survey examined how states were linking data collected by early childhood service providers such as Head Start, Part B, Part C, home visiting, etc.⁹ This survey was not administered to U.S. territories. Results from the survey identified only a portion of U.S. states are linking child-level data from early childhood education providers. Just twenty two states reported the capacity to link child-level data for at least one early childhood program.⁹ Additionally, only 2 of the 50 U.S. states reported the ability to link data across all ECE programs.⁹ Limited states (n=13) reported a data system with the ability to link data across early education programs specific to developmental health. These thirteen states varied in the types of data specific to developmental health that could be linked through the existing data system, such as the completion of a developmental screening, assessment of child eligibility for referral to services, or the ability to track monitor development and progress.⁹

In addition to linking across ECE programming, the Early Childhood Data Collaborative explored which states are linking ECE data to child health services data such as WIC, immunizations, birth records, and/or Medicaid eligibility. Eight states reported their data systems integrate child-level data to this degree.⁹ Similarly, eleven states reported data systems with the ability to integrate ECE data and social services such as child welfare, SNAP/TANF, and/or housing.⁹

There are a number of resources mentioned within this landscape scan that highlight if and how each state integrates their early childhood data and whether or not these data are specific to early detection and identification of developmental delays and autism. [To capture this information, a state by state informational sheet is available for viewing here.](#)

⁹ Child Trends. (2018, September). *2018 State of State Early Childhood Data Systems* (# 2018–43). Early Childhood Data Collaborative.

What are the Benefits of Collecting, Monitoring, and Disseminating Data on the Four Steps of Early Identification?

Each of the early childhood partners mentioned above serve families through their respective offerings and each collects child specific data to the degree in which it's needed for program improvement, reporting, and evaluation. Linking the existing data of these early childhood service providers, as it relates to the four steps of early identification, is essential in understanding:

1. if families are being served effectively across the four steps of early identification.
2. where gaps and barriers related to early identification, referral and linkage exist.
3. which families are being served by multiple early childhood service providers.
4. at what point families maybe lost to follow-up.
5. if family demographics makes loss to follow up more likely.

A coordinated and integrated data system with the ability to monitor families' experience and needs through the four steps of early identification is a system that collects data from a variety of early childhood service providers, links a child's information who might have been served by several services, assigns a unique identifier to protect the child's sensitive information, houses this information securely, and has the ability to disseminate family, community, and state-level data.

Challenges to Integrating Data Systems

Data can be a powerful tool in supporting early childhood services, however, states have experienced obstacles that can hinder integration across partners. Challenges observed through the CIDSEI landscape scan include:

1. Linking various components of early learning and development programs.
2. Data collected are housed in different databases and gathered for various purposes.
3. Many states are not capturing all the child-level workforce-level and program level data needed to answer key policy questions.
4. Gathering and coalescing together requires coordination and buy in of state leaders.
5. Aligning data collection practices to ensure data quality.
6. Securing technical expertise and funds to actually pull all the data together from these various programs.
7. Identifying and hiring sufficient IT staff with all the necessary qualifications alongside retaining staff for long periods of time.

Resources and Toolkits from National and Federal Organizations

The resources listed in this section below helped inform our landscape scan on existing toolkits that have been developed in regards to integrated data systems. The links below include resources on states who have made significant headway in developing their own integrated data systems. We hope to continue to add to this list and ultimately inform our own finalized toolkit for states interested in integrating early childhood data related to the four steps of early identification of developmental delays and autism. In addition to the resources below, Appendix A. includes a glossary of relevant terms and definitions.

AMCHP:

- Title V Early Childhood Data Integration Toolkit. (2017).
<http://www.amchp.org/programsandtopics/CYSHCN/projects/spharc/ChildhoodDevelopmentToolkit/Documents/Title%20V%20Early%20Childhood%20Data%20Integration%20Toolkit%20-%20FINAL%20Fact%20Sheet.pdf>
- Title V Early Childhood Data Integration Toolkit-Use Cases. (2017).
<http://www.amchp.org/programsandtopics/CYSHCN/projects/spharc/ChildhoodDevelopmentToolkit/Pages/Use-Cases-.aspx>
- Title V Data Integration Use Case: Developmental Screening. (2015).
<http://www.amchp.org/programsandtopics/CYSHCN/projects/spharc/ChildhoodDevelopmentToolkit/Documents/Developmental%20screening.pdf>

BUILD Initiative:

- Rising to the Challenge: Building Effective Systems for Young Children and Families, a BUILD E-Book. (2015).
<https://www.childtrends.org/wp-content/uploads/2015/08/2015-35BuildChap7.pdf>

Child Trends, Early Childhood Data Collaborative

- State Early Childhood Data Systems. (2018).
<https://www.childtrends.org/wp-content/uploads/2018/09/ECDC-50-state-survey-9.25.pdf>

DaSy

- Framework Subcomponent: Data Governance and Management (2014).
<https://dasycenter.sri.com/framework/pdfs/DaSy-Framework-Sub-DG.pdf>

Department of Health and Human Services:

- The Integration of Early Childhood Data. (2016).
<https://www2.ed.gov/about/inits/ed/earlylearning/files/integration-of-early-childhood-data.pdf>
- Data Sharing Across Child-Serving Sectors: Key Lessons and Resources. (2019).

<https://www.movinghealthcareupstream.org/wp-content/uploads/2020/01/data-sharing-brief.pdf>

- Integration of Early Childhood Data. (2017).
<https://cbexpress.acf.hhs.gov/index.cfm?event=website.viewArticles&issueid=188§ionid=1&articleid=4985>

Institute of Education Sciences (IES) Statewide Longitudinal Data Systems (SLDS)

- SLDS Early Childhood Integrated Data System Guide. (2011).
https://childcareta.acf.hhs.gov/sites/default/files/public/slds_ec_integrated_data_system_guide.pdf
- What Is an Early Childhood Integrated Data System? (2011).
<https://slds.ed.gov/services/PDCService.svc/GetPDCDocumentFile?fileId=33126>
- Which ECIDS System Model is best for our State ECIDS? (2011).
https://nces.ed.gov/programs/slds/pdf/ECIDS_System_Model.pdf

Nemours:

- Data Sharing Across Child-Serving Sectors: Key Lessons and Resources (2019).
<https://www.movinghealthcareupstream.org/wp-content/uploads/2020/01/data-sharing-brief.pdf>

Health Ranking

- Developmental Screening. (2019).
<https://www.americashealthrankings.org/explore/health-of-women-and-children/measure/devscreen/state/U.S>

Conclusion & Next Steps

This landscape scan yielded a variety of recommendations and best practices for states that are interested in integrating early childhood data. In the next phases of the CIDSEI project, the Help Me Grow National Center and AUCD will conduct a deeper dive into practices and lessons from states leading this work, as well as those that might be experiencing challenges when it comes to coordination and integration of data related to the four steps of early intervention. Key Informant interviews will be integral in understanding how a state identifies the needs, plans, and manages their data collectively as well as illuminate the ways in which states are utilizing integrated data systems to inform practice change, policy, and funding early childhood initiatives. Ultimately, knowledge gained from the landscape portion of this project combined with the information gathered through the interview process will yield the first iteration of a toolkit to be tried and tested by states participating in a three-month-long community of practice.

Appendix A. Relevant Language and Vocabulary

Data Governance: A collection of processes, roles, policies, standards, and metrics that ensure the effective and efficient use of information in enabling an organization to achieve its goals

Developmental Promotion: Individual, group, institutional and/or community strategies (or activities or efforts) intended to advance children's optimal health, development, and well-being. It includes screening and monitoring, but takes a more holistic and upstream view to optimize a child's learning environment and opportunities.

Developmental Monitoring: A continuous, informal process in which families and providers observe children meeting age-appropriate milestones. A provider can engage with a family to inform parent expectations, performs skilled observation of child's development, identify strengths and risk factors, and address concerns, and maintain an up-to-date record of the process and its findings. It occurs in a wide range of professional and community settings. In clinical settings, it is often referred to as surveillance. In addition to improving detection of delays, it builds parental knowledge of typical development so they may nurture their child's growth and seek assessment or services if concerns arise. The integrated process of developmental monitoring/ surveillance accompanied with periodic screening constitute best practice in support of early detection.

Developmental Screening: Use of a brief, standardized tool to periodically confirm a child has reached key milestones for their age. It quantifies the child's progress relative to their peers, supporting timely referrals when progress is not on track. Screening is a complementary activity to informal, continuous monitoring. This too occurs in a variety of settings and can utilize any number of validated tools.

Early Childhood Integrated Data System (ECIDS): A data system designed to collect, integrate, maintain, store, and report information from early childhood programs across.

Horizontal Integration: The practice of linking data across agencies and organizations serving the same client demographic.

State Longitudinal Data System (SLDS): A state-level data system designed to help districts, schools, and teachers make informed, data-driven decisions to improve student learning and allows for data to be collected over the course of the child's educational journey.

Unique Child Identifier (UID): A single non-duplicated number that is assigned to and remains with the child throughout participation in ELD programs and services and across key databases.

Vertical Integration: The linking of data from different data systems that house similar type information. For example linking an ECIDS with an SLDS.

Appendix B. Examples of Responses Related to State and Territory Data Needs for Each of the Four Steps of Early Identification

Step of Early Identification	Responses to Data Needs: Examples of System Barriers
<p>Step 1: Parent-Engaged Developmental Monitoring*</p>	<ul style="list-style-type: none"> • All the data of how many partners are using developmental monitoring is lacking throughout our state. (UT, other) • Few programs are required to report on tracking of developmental monitoring. For example, MIECHV home visitors are required to ask a developmental monitoring question at each visit, but non-MIECHV funded home visitors are not. Unless there is a code for billing for developmental monitoring, it might be a challenge to capture this data (SC, other) • Unified state system for tracking milestone screening data for every child in the state. (VA, other) • Currently, we are only able to systemically pull data reflecting actual screenings through systems and not developmental monitoring. (TX, HMG) • Centralized way to collect data about developmental monitoring. (IN, other)
<p>Step 2: Developmental and Autism Screening^</p>	<ul style="list-style-type: none"> • We don't have a way to track if children truly are getting screened multiple times. (IA, Part C) • Statewide population level data on % of developmental and autism screening via consistent use of VT's developmental screening registry. Registry data can be cross-walked with VCURES claims data for quality improvement in screening rates in medical practices. (VT, other) • Community wide developmental screening information not just from Medicaid and referrals made accordingly (OH, WIC) • Access to Medicaid Claims data that shows screenings conducted by provider agencies (NC) • Differentiation between developmental screening / ASD screening codes used by providers (NC, Part C) • A screening registry to reduce redundancies. (CA, HMG) • Centralized data repository to provide Head Start Screening results. Or a way that the school district can access these results from a centralized location. (ID, HS/EHS) • We desperately need a statewide database for developmental screening. We have no way of knowing what % of children have been screened. (FL, HV) • Data which shows the communities where there are high percentages of children being identified at or after the age of 5 is currently not publicly available. (HI, other) • The statewide ASQ Online system needs to be configured differently and utilized by all providers for a better and bigger picture of our data needs. (AK, ECCS)

Step of Early Identification	Responses to Data Needs: Examples of System Barriers
	<ul style="list-style-type: none"> • Local data is not always shared between providers who conduct screenings. It could be helpful to have local level coordination of data to avoid duplication and ensure proper placement. (WY, HS/EHS) • Need a central repository for collecting and tracking data. There is likely duplication of screening, and no way of tracking it (primary care, childcare, home visiting, etc.). (IA, other) • As a state, MS does not collect data on developmental and autism screening in general. It would be great to have a standardized system for this within our state. (MS, disability advocacy) • Data on how many children are identified from screening and early identification. Data on positive outcomes for children who are identified early. (OK, HS/EHS) • Any developmental screening information should be shared across partner agencies for families to obtain especially in their communities. (VA, HS/EHS) • Rates of timely screens. (VT, HS/EHS) • Percentage of pediatricians, by geographical regions, who complete timely developmental and autism screening. (PR, Title V) • Knowing the amount of agencies using developmental screeners and way to share the screeners. Systematic way to share all the data (UT, other) • Comparative data that includes general developmental, autism, social-emotional, and maternal depression screening. (MN, AAP) • In NC we have been lucky to be able to track developmental screening rates through Medicaid billing. That way when we implemented and intervention we were able to see the effects. However this is in jeopardy as we move through Medicaid transformation. (NC) • After that step is established there needs to be a way to track referral rates and service provision rates. (NC, ECCS)
<p>Step 3: Referral for Services[^]</p>	<ul style="list-style-type: none"> • Referral follow-through information from referral sources on outcomes of patients referred to their groups. (UT, other) • The number of requests for assessments vs. how many take place (and the length of time between the two). (OR, HMG) • data related to follow-up / closing the loop. it's great that screening occurs, and it's also important to know follow-up on referrals. Some of this could include more data sharing amongst systems. (MN, Title V) • We have HMGVT data on # of referrals to Children's Integrated Services, but we need regular and accessible reporting and Part C Early Intervention data on # of referrals from HMGVT and others for better understanding of and integration of services. (VT, other) • Types of families getting referred; what agency referred- not from parent report (UT, Part C) • What happens to families who do not qualify for EI services (TX, HMG) • More internal reporting on referral usage and where there are gaps that need attention. (OH, WIC) • Ability to track services for a family or child across programs (CA, HMG)

Step of Early Identification	Responses to Data Needs: Examples of System Barriers
	<ul style="list-style-type: none"> • Number of families who do not follow up on referral - differences by race, language, culture, area of state. (SD, other) • Of children with scores below the cut-off, how many are referred, how many are evaluated, and how many qualify and receive services? (FL, HV) • Data around what makes referrals for early intervention services successful (IN, HS/EHS) • Local level and individual child data is not consistently shared between providers in every community. (WY, HS/EHS) • What services are children receiving the most and why? (MN, other) • The number of children who screen positive for autism or developmental delays and how many actually receive a referral. (MS, disability advocacy) • How many referrals are made vs. how many end up receiving services. And why? What barriers kept them from accessing the referrals- not believing their child needed services, not following up with referral, money, time, transportation, etc. (OK, HS/EHS) • Do we currently track the number of children who are identified in early childhood, but their families request that they no longer need the services latter in their academic experiences? (VA, HS/EHS) • Better information and coordination of referral data (who refers) and outreach efforts (who is outreaching to who to avoid duplication) (VT, other)
<p>Step 4: Receipt of Early Intervention^</p>	<ul style="list-style-type: none"> • The number of Part C children that initial decline Part B services then, later access Part B services. The number of Part C children that exit Part C prior to turning age 3, do they end up receiving Part B services. (HI, Part C) • How are families perceiving benefits of EI to their child now that delivery may have changed due to COVID. (SD) • Are providers able to deliver effective services via telemed, how do we know. (SD, other) • Data around success rates for early intervention services and data around what surrounding supports can be supplied that increase the likelihood of early intervention services success would both be helpful. (IN, HS/EHS) • Again, child-specific data is not consistently shared within communities in which multiple service providers are involved. (WY, HS/EHS) • How long are wait lists on average. how long are children receiving services. (MN, other) • Longitudinal outcome data regarding the benefits of the receipt of early intervention services within our state. (MS, disability advocacy) • How many children are referred and don't qualify for Part C and why. (OK, HS/EHS) • How many children are currently eligible but not receiving services due to lack of identification. (VA, HS/EHS) • Family identified barriers to engagement with Birth to 3 Program; Reasons for early disenrollment; What services and supports are most effective in supporting families to feel confident in supporting their child's development. (WI, Part C)

Step of Early Identification	Responses to Data Needs: Examples of System Barriers
	<ul style="list-style-type: none"> • Data on child progress since the implementation of telepractice services. Year to year comparison to analyze the impact of COVID-19. (HI, Part C) • In Iowa we have a hard time knowing how much service a child in EI received. (IA, Part C) • Connect the Health Department’s UDS registry to the Agency of Education’s State Longitudinal Data System, under Act 166 PreK required to use HMG ASQ online system, better coordination of screening data, referral data to streamline getting into services, examine trends (VT, other) • Reach of all early intervention services across TX (TX, HMG) • The number of children NC is missing who could benefit from early intervention services but are not. (NC, Part C)

Note. HV = Home Visiting; ECCS = Early Childhood Comprehensive System Grantees; HS/EHS = Head Start/Early Head Start; CW = Child Welfare; HMG = Help Me Grow; WIC = Supplemental Nutrition Program for Women, Infants, and Children

*All responses included

^Includes only the first 50 responses in the needs assessment

Appendix C. Questions from Respondents about Data Needs for Step 1: Parent-Engaged Developmental Monitoring (PEDM)

- What programs and tools are being promoted in this [added: PEDM] arena. How many parents are engaged in this. (UT, HMG)
- Family engagement data and data on how programs are using LTSAE materials and engaging families in developmental monitoring. (VT, other)
- What programs across the state/region are using materials/which ones; parent feedback on current materials and how they are/aren't helpful to them; see outcomes from materials to final outcomes. (screenings, etc., TX, HMG).
- How many families would be interested and are actually doing it. (NC, Part C)
- Percentage of state parents engaged in developmental monitoring (SD, other)
- Specific resources providers/systems are connecting families with to engage in developmental monitoring - what, who and where. (SD, other)
- Is there data around parent-engaged developmental monitoring in the African American and Hispanics populations that is extensive and well researched? Maybe this is data that is lacking. (OK, HS/EHS)
- Age of identification and intervention services for those children whose caregivers engaged in developmental monitoring birth-5 vs. age of identification and intervention services for those children whose caregivers did not engage in developmental monitoring. (MS, disability advocacy)
- More consistent data on what childcare programs are engaged in developmental monitoring (ID, ECE)
- Data that helps us identify characteristics of families who are already using parent-engaged developmental monitoring and characteristics of those who have been targeted but are not engaged, would be useful. In what ways are those populations different and how might the materials or outreach strategies be more targeted to appeal to different populations. (SC, other)
- Region-specific data - who is submitting, percent of children with suspected delay, # of children referred, etc. (NH, other)
- How many age appropriate milestone checklists are completed in quarter. (IA, other)
- How many ECE's, pediatricians, etc. in the state have adopted developmental monitoring and screening? (VT, other)
- How many parents are actually using developmental monitoring with their children and bringing up any concerns with their medical provider. (GU, other)
- The number of parents who have materials and data on usage which results in referrals for early intervention. (ND, other)
- Unduplicated #s, Number of monitoring screenings that lead to referrals for evaluations, Number of referrals for evaluation that result in an evaluation (DE, HS/EHS)
- How do parents receive their information and from who (IA, disability advocacy)
- We are unsure how many families the digital divide is impacting which makes it difficult to determine how best to support. (NY, HMG)
- What happens after families receive information from the various programs/partners? How many families actually use the information to engage in developmental monitoring? (NJ)
- What % of parents/caregivers are engaging in developmental monitoring? Of those who do engage, who are they connecting with about this info -- pediatrician or someone else? If not a

pediatrician, are they being linked to a medical home to support their child's global health?
NJ, AAP)

- Reporting system for parents (like a parent portal) to gather information. (WY, Part C)
- Percent or number of KY population accessing parent-engaged dev. monitoring broken down by ADD districts and counties. (KY, other)
- What primary care clinics are actually communicating about parental developmental monitoring and what materials they are using. (CO, other)
- Whether developmental monitoring is equitable. (OR, HV)
- How many parents successfully do this? (UT)
- Do we know if parents who are dealing with abuse and neglect are less likely to do this? (UT, CW)
- Are parents being requested to do this by multiple agencies/providers to look at how better to coordinate this (VA, other)
- Who is conducting PEDM and how many children are receiving, where, and from whom. (GA, other)
- How many parents are engaged, what activities are they engaging in, what barriers are they experiencing? (FL, ECCS)
- Who received material about parent-engaged developmental monitoring, used it and identified developmental delays. (PR, Part C)
- Who is doing monitoring; how did they learn about it; what did they do with the information; who did they share the results with; did they get connected to supports and services (WI, Title V)
- Community specific number and type of programs that offer parent-engaged developmental monitoring outside of PCP practices for better coordination between the physician and community resources. (AL, AAP)
- How many children are at risk in our state?
- How does parent-engaged developmental monitoring improve children's outcomes? (MT, other)
- Communication between the medical / Professional systems and the educational Part C/B systems. Right now there is a big gap in what doctors are monitoring and what they are doing with that information. We see too many physicians play the "wait and see" system rather than "refer and get further guidance and direction." The latter being the most effective and needed. (UT, Part C)
- Having a centralized data collection of knowing and understanding all the partners that are conducting parent engaged developmental monitoring. (IN, HMG)
- The benefits of starting developmental education to parents when the child is in the womb and the continuation of education and how to monitor at recurring appts after child is born. (SC, Title V)
- Maybe something parents could complete in MyChart and be incentivized if all were completed? MyChart could send out automatic reminders for parents at specific intervals. (WI, Title V)
- Understanding at which ages parents are most confident in assessing development vs others. What they see that concerns them vs makes them want to "wait and see" (MN, Title V)
- What are the most common milestones at which ages to be behind on, specific to nutrition (for our purposes). So for instance, if using a spoon by age 18 months is really important, and a high proportion of children are lagging on this, it could be something we focus on, or gather more resources on to share with parents. (MT, WIC)

- How successful are we at improving child outcomes from parent-engaged developmental monitoring? Where has it been successful? How do we do it when families have to work? (NC, ECE)
- Why parents decline to follow-up on their child's hearing status (UT, other)
- The number of families that refuse services (WV, ECE)
- How much of the monitoring in our state is parent-engaged? (MT, HS/EHS)

Appendix D. Examples of Year One Response Team Activities

Focus Areas	Examples of Activities
Communication & Dissemination	<ul style="list-style-type: none"> Use of Media Use of Media Influencer Disproportionally Affected Communities Customized Materials Created a Kit Distributed to Families Distributed to Providers Mass Mailing Use of website
Training	<ul style="list-style-type: none"> Trained Families Trained Providers Trained a Program Community of Practice or Professional Learning Community Use of an Action Plan Train the Trainer Model Archived Recorded Training Created a Training Materials
Policy Efforts	<ul style="list-style-type: none"> Required Use of Same Materials Across a Program or System Training is a Program or System Requirement Created a Centralized Access Point Changed a Program or System Policy Use of a Memorandum of Understanding Braided Funding Research on the System to Inform Policy Leveraging other Initiatives in the State or Territory

Appendix E. Generalized Data Needs for Early Identification

- Coordinated data at the state level between Early Intervention and CYSHCN (MS, Title V)
- Close loop referrals so that we can see that providers are talking to one another to support the family and not all of it on the family. (NH, HV)
- Data systems do not share information among departments (CA, disability advocacy)
- Any data would be helpful. Much of what is collected is very scattered and/or unavailable to a wide audience of stakeholders. (WY, HS/EHS)
- There is data available from a multitude of programs operating in our state, but accessing, analyzing, and reporting on the data requires funding. (SC, other)
- A centralized data base for each state, such as the data based used for immunizations of children. Having a centralized system would follow the child and would allow providers to see where the child is in their development. (WV, HV)
- Data across sectors that can be shared. (CT, other)
- A centralized database to capture all providers screening and evaluation information. (DC, CW)
- Not so much what data, rather, cohesive data collection that can be analyzed and shared among all stakeholders including parents! (CT, HMG)
- An integrated database that would be accessible by all providers. (VT, other)
- Tie data from all the EC silos together in a way so that it is meaningful and useful to programs. They need to build capacity to make evidence--based decisions that in turn will bolster the programs in which early intervention is working with families - data contributes to this. However, to use date effectively, decision makers need to receive ongoing support and training to understand how to use the data and understand what it is telling them. (MN, other)
- Common data collection system across all services. (CA, disability advocacy)

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