

Impact of the COVID-19 Pandemic on Early Identification of Developmental Delays and Disabilities and Opportunities for Improvement

A Summary of Findings from the Act Early Response to COVID-19 Needs Assessment



**Centers for Disease
Control and Prevention**
National Center on Birth Defects
and Developmental Disabilities



Project Overview

The Act Early Response to COVID-19 project (Act Early/COVID-19) is a federal, nationwide initiative to support families with young children and early childhood systems with early identification of developmental delays and disabilities. In addition, this initiative aims to promote resiliency among families with young children during the COVID-19 pandemic. The project is funded by the Coronavirus Aid, Relief, and Economic Security (CARES) Act of 2020 through a cooperative agreement (6 NU38OT000280-02-02) between the Association of University Centers on Disabilities (AUCD) and the Centers for Disease Control and Prevention (CDC). As part of this initiative, 43 state and territorial Act Early Ambassadors were awarded a 1-year grant to 1) establish and engage an Act Early Covid-19 Response Team of key early childhood system/program partners, 2) identify and address needs related to early identification of developmental delays and disabilities during the COVID-19 pandemic, and 3) promote resiliency among families with young children during the COVID-19 pandemic.



Identifying Needs Related to Early Identification During the COVID-19 Pandemic

In fall 2020, AUCD and CDC conducted a rapid needs assessment. The primary purpose of the assessment was to describe the impact of the COVID-19 pandemic on early identification of children with developmental delays and disabilities. The needs assessment identified current and emerging needs, barriers, strengths, and opportunities for early recognition of developmental delay and disability among children from birth to age 5 years during the pandemic. The assessment included early childhood programs and systems. Two web-based surveys were conducted: one survey with grantees ($n = 43$) and one survey with the 43 grantees' early childhood partners in their states/territories ($n = 349$). Data were summarized using mixed methods. A content analysis, using a coding scheme based on the social ecological model, was conducted and descriptive statistics were calculated.



Summary of Key Findings

Impact of COVID-19 Pandemic on Early Identification



- A majority (91%; n = 345) of respondents indicated that the COVID-19 pandemic “highly impacted” early identification of developmental delays and disabilities in young children from birth to age 5 years.
- Nearly half (48%; n = 131) of respondents reported the number of children served by early childhood programs and systems overall has decreased since the COVID-19 pandemic started. Qualitative data collected from programs and systems indicate that the decrease in children served could lead to a negative impact on early identification.
- A majority of programs/systems have transitioned to hybrid service delivery (i.e., a combination of virtual and in-person) since the start of the pandemic, including:
 - » 57% of programs/systems that provide referral for early intervention services
 - » 66% of programs/systems that provide developmental and autism screening and early intervention services

Multilevel Impacts on Early Identification and Service Delivery

The COVID-19 pandemic has had a multilevel impact on early identification and service delivery including



- Reduced allocation of resources for this work (e.g., staffing, funding, and time)
- Poor service delivery coordination
- Communication challenges between families and providers
- Misconceptions about service availability
- Competing priorities as families struggle to meet basic needs of living

For example, as one respondent explained, “families are not engaging with service providers who encourage developmental monitoring as frequently, and they are also not interacting with others especially similar age peers to trigger questions about development.”

Respondents reported that the COVID-19 pandemic has exacerbated existing barriers to receiving services and further added stress on systems already lacking funding and coordination. One respondent stated that many programs/systems were “insufficiently and unsustainably funded” prior to the pandemic. “During the pandemic, the precarious early childhood education and care infrastructure has been financially devastated as many families keep their children home for health and safety.”

Identified Needs

Respondents cited the following as most needed to improve early identification of developmental delays and disabilities:



- Resources (e.g., staffing, funding, and time) to appropriately deliver services
- Training for staff, providers, and families
- Greater innovation in strategies to support families
- Resources to address underlying causes of health inequities to help families

Respondents also reported a need for better collaboration and coordination to support information sharing between programs/systems. They also need simpler processes so families can use these programs.



As one respondent stated, “[providers] do not have an easy, consistent way to share information on children receiving care in multiple settings. Providers would benefit from having real-time access to data portraying a more holistic picture of a child’s care network and health status over time; [this will help them to] work collaboratively, avoid duplicating efforts, and measure intervention outcomes and benefits throughout their development.”

Respondents indicated many of the identified needs existed long before the pandemic. They became more apparent as the country shut down and programs and systems closed or reduced enrollment and capacity.

Barriers to Early Identification

The needs assessment noted the following as barriers to early identification of developmental delays and disabilities:



- Insufficient resources (e.g., staffing, funding, and time)
- Limited access to technology to support families remotely
- General lack of awareness and understanding of developmental milestones and early intervention among staff members, providers, and families
- Lack of culturally and linguistically appropriate materials for families
- Societal stigma associated with developmental delays and disabilities

Respondents said challenges related to financial reimbursement (e.g., billing and health insurance) were also a problem, noting that the COVID-19 pandemic amplified existing barriers.

“Inadequate reimbursement for well-child visits discourages sufficient time spent with child and family to conduct screens and discuss developmental concerns.”

Strengths and Opportunities

Reported strengths and opportunities to improve early identification of developmental delays and disabilities during the COVID-19 pandemic included



- Increased ability to reach and screen more children in a virtual environment because former barriers to access (e.g., transportation) were no longer present
- Greater support for new, innovative ways to support families
- Ability to provide more comprehensive services to families (e.g., food assistance, housing assistance, and mental health services)

Respondents said increased collaboration and partnerships among programs/systems was a notable strength and opportunity that emerged from the COVID-19 pandemic. For example, one respondent said programs were “creating new partnerships to leverage resources and connect children and families to resources they may not have needed in the past.”

Respondents also sought greater openness and consideration of new partnerships to facilitate early identification, including partners from

- Private organizations (e.g., clinicians and healthcare providers, technology companies, and internet providers)
- Education (e.g., childcare providers and university medical training programs)
- Community (e.g., families, faith-based organizations, and grassroots, community-based organizations)
- Government agencies and public organizations (e.g., local, state, Tribal, territorial, and federal governments, payers and insurance providers, and food banks)



Conclusions

Early childhood programs and systems report that early identification of developmental delays and disabilities among children from birth to age 5 years have been greatly impacted by the COVID-19 pandemic.

While some challenges to early identification are new, the COVID-19 pandemic has amplified the needs and barriers to early identification that existed before the pandemic.



Next Steps

To best support children and families, strategies for improving early identification will need to address both new and existing, and now worsened, challenges.

Early childhood programs and systems were able to leverage existing strengths and recognize opportunities to support more families comprehensively. However, respondents cited a need for innovative strategies, resources, and collaborative partnerships to realize these opportunities.

Strategies will need to prioritize change within systems, and at the parent-community level, to improve early identification of developmental delays and disabilities among young children.

Findings from this needs assessment will support grantees in refining project work plans. These findings also will guide project implementation to address identified needs, barriers, strengths, and opportunities related to early identification of developmental delay and disability among young children during the COVID-19 pandemic. These findings can also inform efforts to support early identification of developmental delays and disabilities among young children and improve resilience among families, now and in future public health emergencies.