

Act Early Response to COVID-19: Supporting the Early Identification of Young Children with Developmental Delays or Disabilities

AUCD Early Childhood SIG

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



Project Scope & Purpose

Scope:

43 state/territorial Act Early Ambassador-led (or co-led) teams prioritize families most impacted by COVID-19 to ensure early identification and foster the resiliency of children, families, and communities.

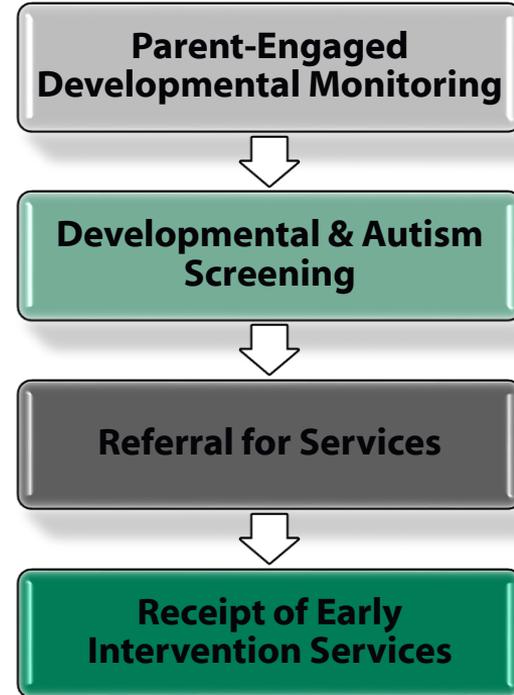
Purpose:

- Bolster the 4 steps of early identification of developmental disabilities including autism by integrating LTSAE into early childhood programs.
- Advance the promotion and distribution of tools, materials, and programs to improve resiliency among families with young children during the COVID-19 response and mitigation efforts.



What is early identification?

The 4 Steps of Early Identification



LTSAE Levels of Integration Framework

Level 1: Passive promotion of LTSAE materials

Level 2: Active distribution of LTSAE promotional materials

Level 3: Routine training of staff (e.g., using *Watch Me!*)

Level 4: Active distribution of LTSAE checklists

Level 5: Active completion of LTSAE checklists with families

Project Goals

1. Develop and coordinate an Act Early Ambassador-led (or co-led) state/territorial team
2. Engage the state/territorial team in conducting a needs assessment to identify CURRENT (*during COVID-19*) barriers and opportunities related to the four key steps of early identification
3. Develop, implement, and evaluate a work plan to address identified barriers; realize the identified opportunities related to parent-engaged developmental monitoring; AND any of the additional 3 steps of early identification
4. Identify, implement, and evaluate strategies to improve resiliency of very young children (birth to age 5) and their families



Goal 1: State/Territory Partner Leadership Team

Required Partners Listed in the Grant Request for Application

- Title V
- Individuals with Disability Education Act (IDEA) Part C
- Help Me Grow
- Early Childhood Comprehensive Systems grants
- American Academy of Pediatrics
- Disability Advocacy
- At least 1 high reach statewide: Head Start/Early Head Start, Home Visiting, Women Infant & Children, Child Welfare, Early Care & Education

Additional Partners

- Family Advocacy
- Higher Education
- University Centers on Excellence in Developmental Disabilities
- Leadership & Education in Neurodevelopmental & Other Related Disorders
- IDEA Part B, 619
- Medicaid
- Private Non-Profit



The State/Territory Partner Leadership Team



The state/territory partner leadership team facilitates a holistic approach for early identification during the COVID-19 pandemic

Examples of Team Partnerships

- **NY:** Utilizes the state team as a professional learning community
- **SD:** State team partners prioritized and ranked needs to select interventions/activities
- **WY:** State team partners are participating in the Extension for Community Healthcare Outcomes (ECHO) trainings
- **SC** and **UT** Partners on the team are integrating LTSAE materials
- **AR:** Family Advisors implementing LTSAE in HealthySteps sites are part of the leadership team



Goal 3: Develop & Implement a Work Plan

Strategies for Integration of LTSAE

- Material dissemination
- Material development
- Training
- Community Liaisons

Integrate LTSAE into Early Childhood Programs

- Integration supports early identification
- Primary focus is on parent-engaged developmental monitoring
- Programs selected should have a broad reach in terms of the number of children & families



Develop & Implement a Work Plan- *Monitoring & Screening*

■ **Developmental Monitoring**

- **FL:** Developed a postcard with a QR code to drive parents to their website and online checklist (3,000 visits)
- **OK:** Created a sticker to put on materials with the URL to the landing page for LTSAE for a local Head Start agency with 7 sites
- **Screening**
 - **HI:** 75 medical students (Deputy Ambassadors) received training to administer screening *The Survey of Young Children's Well-Being*
 - **CT:** Parents use of the Sparkler App includes both LTSAE & the Ages & Stages Questionnaires®-3rd Edition (ASQ-3) for screening; all data is reported to United Way



Develop & Implement a Work Plan- *Referral & Early Intervention*

■ Referral

- **CT:** Provides care coordination through United Way to families when a screening reveals a concern
- **NH:** Creating a single system access point for families; if a screen identifies a red flag there is one place for families to go for a referral

■ Early Intervention

- **IN:** Part C infused LTSAE into all states Child Find materials to create one consistent message on early identification
- **IL:** Part C provider experiences in the Extension for Community Healthcare Outcomes (ECHO) training used by agency administration to make changes addressing knowledge and needs



Develop & Implement a Work Plan- *Examples of Material Development*

- **AK:** Adapting each of the 3 LTSAE board books so illustrations & stories are culturally relevant to Native Alaskan communities
- **FL:** Created a social media toolkit for Help Me Grow affiliates
- **OH:** Leadership Education in Neurodevelopmental and Related Disorders (LEND) trainees developing a physician's toolkit
- **PR:** Undergraduate students from Sacred Heart University creating 3 videos
- **ID:** Created a resiliency toolkit for providers to use to support families
- **MA:** Developing and implementing webinars for a variety of early childhood providers on LTSAE



Develop & Implement a Work Plan-*Examples of Training Strategies*

- **CT:** Creating a playbook of how to use LTSAE to support training for early childhood providers
- **IL:** Developing home visiting training module that will be a part of their training package for providers
- **IN:** Creating a narrated PowerPoint and Implementation Guide to provide statewide training to Head Starts on use of LTSAE for family engagement, monitoring, and screening
- **ND:** Creating monthly mini-lessons and Loom (video messaging tool) about LTSAE materials to train Head Start/Early Head Start
- **OH, VA, WY:** Collaborated to implement an ECHO for any type of early childhood provider



Develop & Implement a Work Plan- *Examples of Community Liaisons*

- **AR:** Family Advisors help family voices be a part of advocating for change
- **FL:** 13 Help Me Grow Affiliates have a memorandum of understanding with the state Ambassador
- **LA:** Will work with 5 *Ready Set Networks* (LA Department of Education) in the state to become community leaders
- **NJ:** Recruiting Parent Champions to disseminate LTSAE to families & other community agencies & work with pediatric residents
- **TX:** Recruited 12 Deputy Ambassadors from a variety of state and local programs from each region of the state who created action plans describing integration of LSAE



Goal 4: Resiliency of Children & Families

Interventions

- **HI:** Use of the *Survey of Young Children's Well Being & Parent Cafés* (a developmental screening)
- **NE:** Using *Lemonade for Life*
- **LA:** Using *Safe, Secure, Loved* to teach parents resiliency building techniques
- **VA:** Working with cultural brokers
- **VT:** Using a state-wide framework on resiliency developed with partners

Trainings

- **NC:** State-wide conference on infant and early childhood mental health
- **FL:** 2-hour training for Help Me Grow affiliates on trauma
- **KY:** Developing a virtual training on resiliency for all early childhood system partners
- **DC:** Will conduct virtual *Parent Cafés*



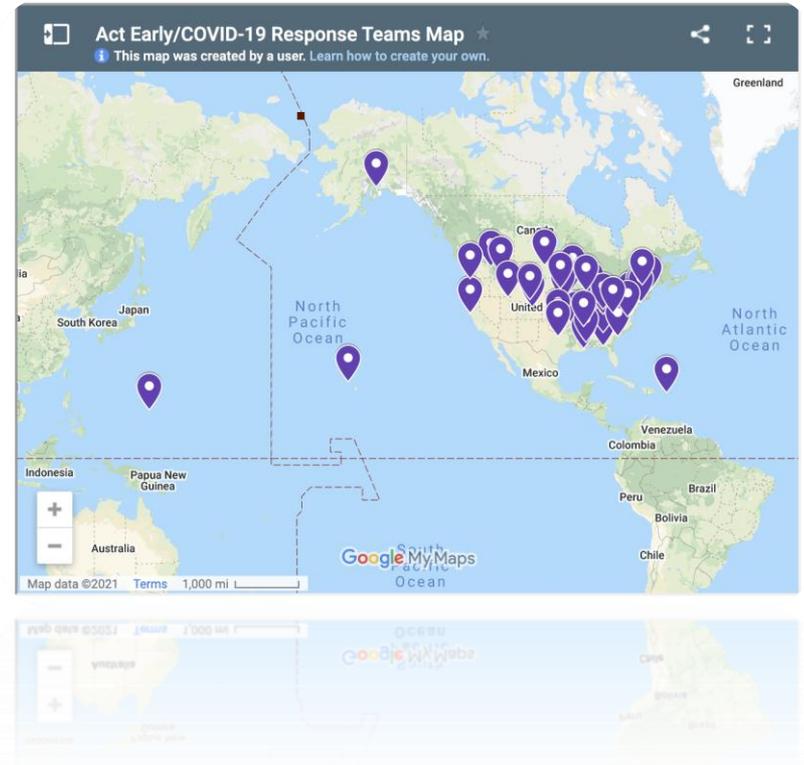
Goal 4: Examples of Supporting Community Resiliency

- **AK:** Works in collaboration with different Native Alaskan communities, including tribal councils, to create a companion document for the ASQ-3 so items are culturally relevant and meaningful for families
- **OR:** Training parents who are migrant seasonal farmworkers to provide virtual home visits in their community with families of young children

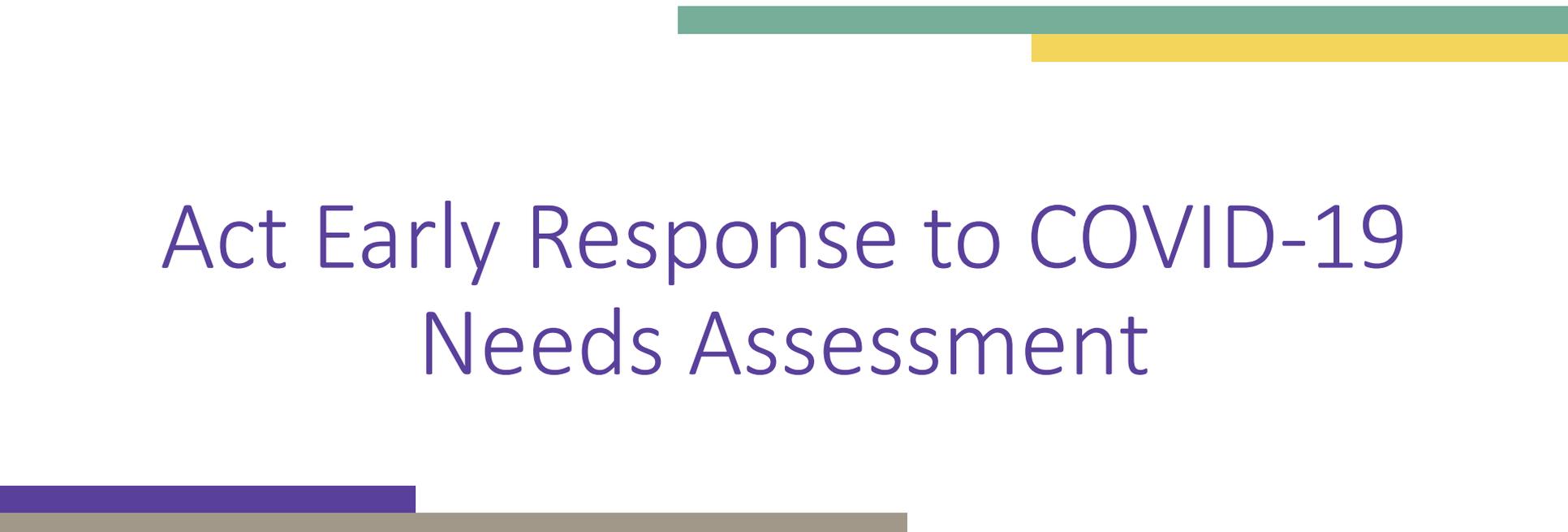


43 Unique State/Territory Projects

This map highlights the work the 43 State and Territorial Response Teams are executing as part of this one-year grant opportunity. By clicking on each pin, you can learn more about each Team's project activities.



[Act Early/COVID-19 Response Teams Map - Google My Maps](#)



Act Early Response to COVID-19 Needs Assessment



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Disclaimer

Disclaimer: The findings and conclusions in this presentation have not been formally disseminated by the Centers for Disease Control and Prevention and should not be construed to represent any agency determination or policy.

The Act Early Response to COVID-19 needs assessment survey is cleared under the Public Health Emergency (PHE) Paperwork Reduction Act (PRA) Waiver provided by Health and Human Services (HHS) which allows CDC to monitor, assess, respond to, and mitigate the impact of the COVID-19 pandemic, including, but not limited to, collection of information from states, laboratories, and healthcare providers about COVID-19.



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Purpose: To understand current and emerging **needs, strengths, barriers, and opportunities** related to the **four steps of early identification** of developmental delays among children birth to 5 years the during COVID-19 pandemic, across early childhood systems and programs.

Methods



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Design:
Primary data
collection via 2
web-based
Qualtrics
surveys
administered by
CDC/AUCD

Team Lead Survey

- Administered and disseminated by CDC/AUCD
- Completed by Act Early Response to COVID-19 **team leads**
- Gathered **overall state/territory** information related to the 4 steps of early identification

Partner Survey

- Administered and disseminated by CDC/AUCD, with introductions and reminders shared by team leads
- Completed by the representatives of key **partner programs and systems** listed on response teams' work plans serving children birth to 5 (e.g., Part C, WIC, Home Visiting, Early Head Start)
- Gathered **specific early childhood program and system** information related to the four steps of early identification



Survey Measures

Engagement in 4 steps of early identification	Activities and initiatives	Strengths	Barriers
Supports	Partnerships	Changes since COVID-19	Data strengths and gaps/needs
Existing data sources ^a	Data (e.g., # of referrals to Part C) ^a	LTSAE campaign awareness and levels of integration ^a	Demographics

^a Partner survey only



Data Analysis

Data integration included 3 steps:



Response Teams data review

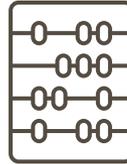
Data returned to teams to
summarize using template

Data Analysis

Data integration included 3 steps:



Response Teams data review



Quantitative data analysis

Data returned to teams to
summarize using template

Basic descriptive statistics in
SPSS

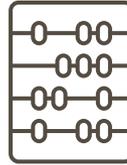
Data Analysis

Data integration included 3 steps:



Response Teams data review

Data returned to teams to summarize using template



Quantitative data analysis

Basic descriptive statistics in SPSS



Qualitative data analysis

Content analysis

Three coders applied codes in Dedoose using a coding scheme based on the social ecological model



Key Findings



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Respondent Characteristics (*n* = 392)

 Partner survey: *n* = 349

 Team lead survey: *n* =
43

 74.3 % have master's degree or higher

 89.8% identify as female

 39 years \pm 36.9 years

Range of partners invited per state/territory: 5-48

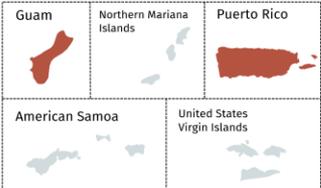
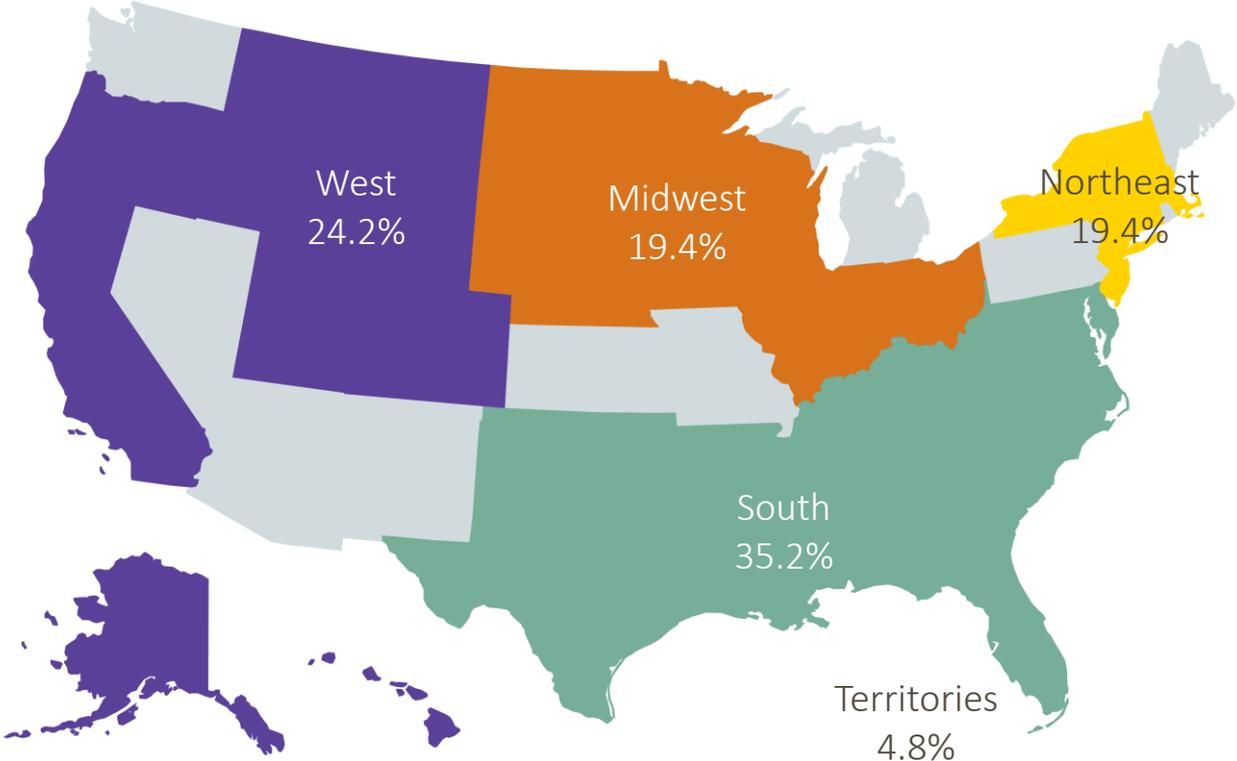
Range of surveys completed per state/territory: 2-17



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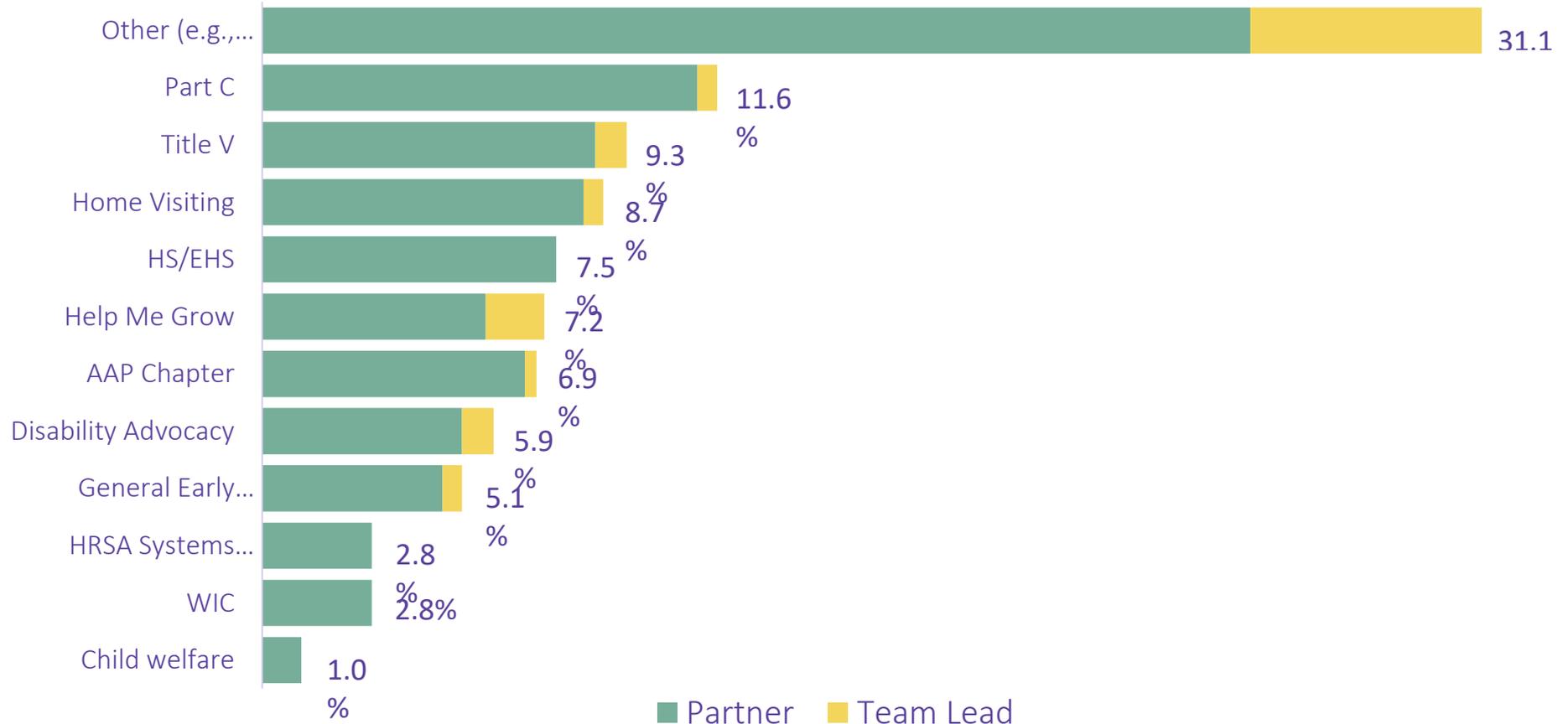


More than one-third (35%) of responses were from the South ($n = 392$)



Note: gray areas on map are states/territories that are not participating in the Act Early COVID-19 project

Nearly one-third (31%) of respondents reported “Other” for their program/system, followed by Part C (12%) and Title V (9%; *n* = 389)



Early Identification Overall

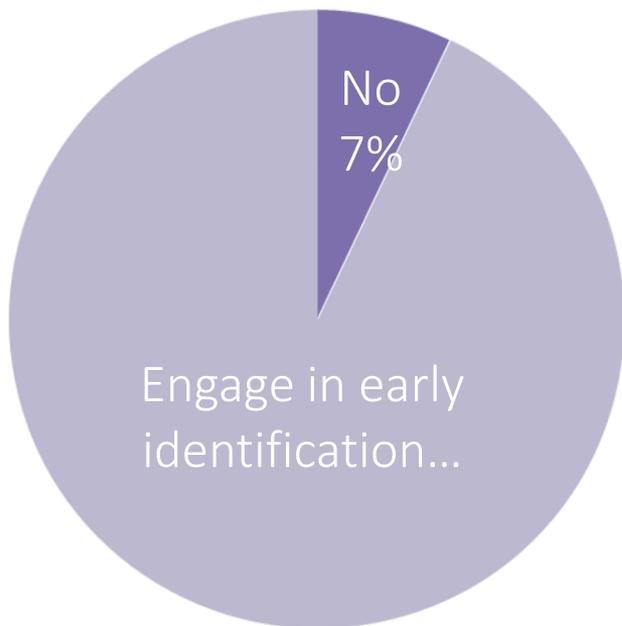


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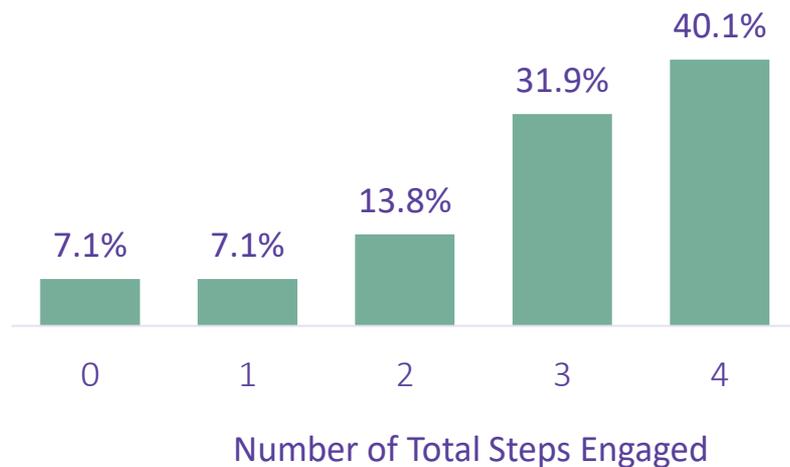


Engagement in Early Identification Overall

93% engaged in **some** early identification ($n = 392$)

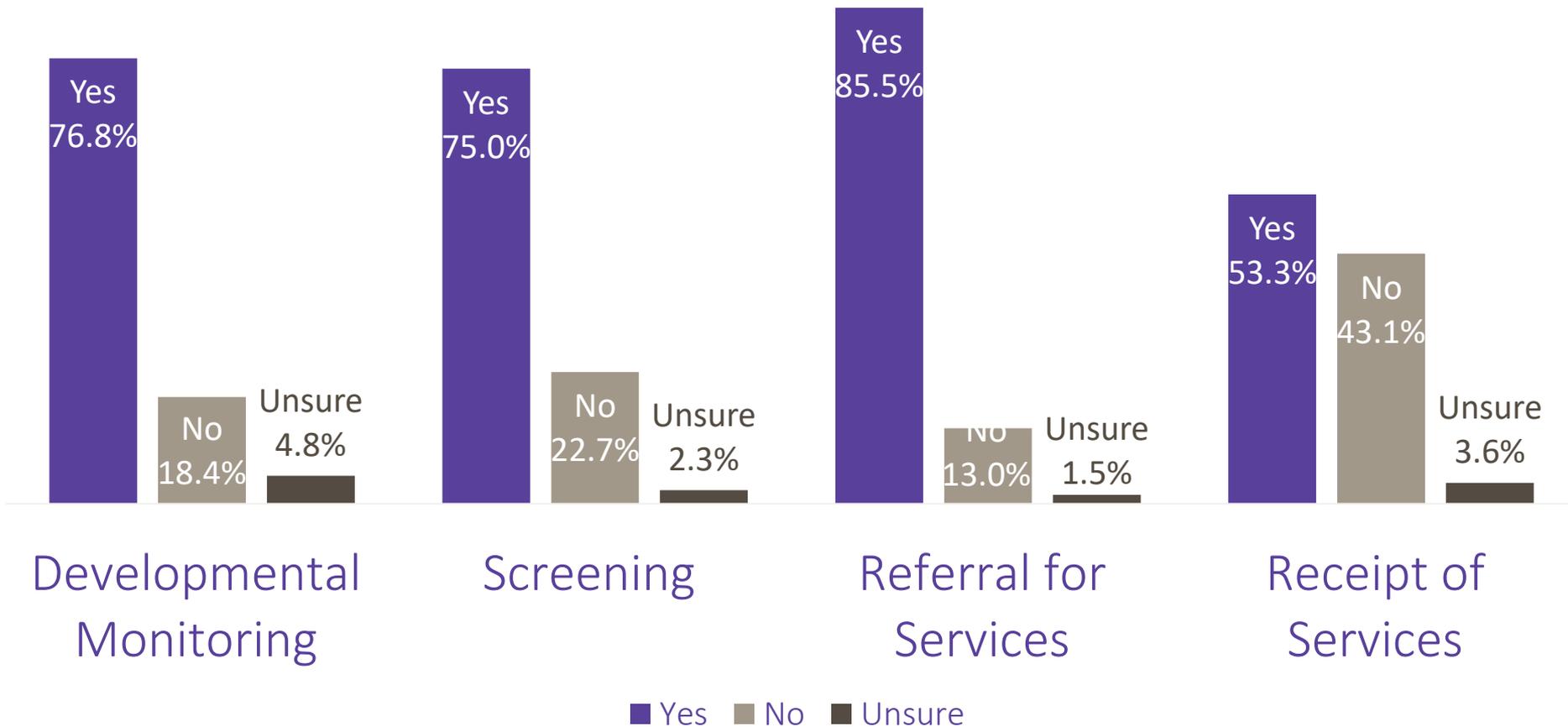


Most engaged in **at least 3** of the 4 steps of early identification

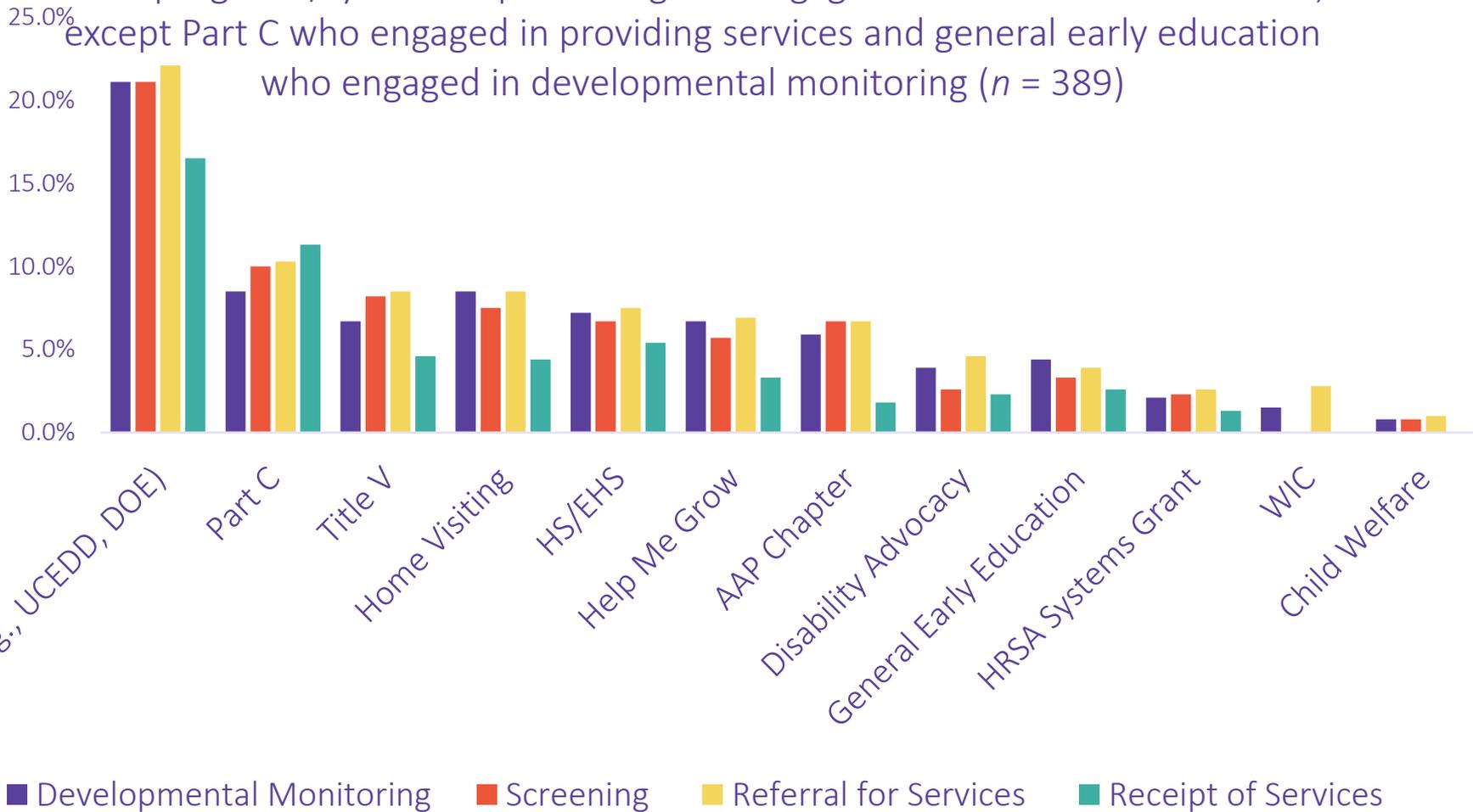


Average number of steps engaged = 2.9 ± 1.2

Over **85%** of respondents reported engaging in **referral for services**, closely followed by developmental monitoring (77%) and developmental and autism screening (75%; $n = 392$)



Most programs/systems reported highest engagement in **referral for services**, except Part C who engaged in providing services and general early education who engaged in developmental monitoring ($n = 389$)



COVID-19 Impact on Early Identification Overall

- »»» **91.3%** indicated COVID-19 has **highly impacted** early identification ($n = 345$)
- »»» Only **2.6%** reported COVID-19 had **no impact**
- »»» **48.0%** reported number of children served has **decreased** (31.9% unsure; $n = 119$)

COVID-19 Impact on Early Identification Overall

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Examples of COVID-19 Impact on Early Identification



Collective trauma due to COVID-19



Decrease in screening, referral, evaluation



Competing priorities to meet basic needs



Poor program and system **coordination**



Change in service delivery to **virtual**



Resources (i.e., staffing, funding, time)

Barriers

- Provider/staff awareness and knowledge of DM
- Family awareness of DM and interest in engaging in DM
- Resources (i.e., staff

Needs

- Consistency and repetition in messaging from staff/providers across programs/systems
- Empower families to generate

Step 1

Developmental Monitoring

Strengths

- Programs/systems finding innovative ways to support families
- Changes in reimbursement due

Opportunities

- Increase reach via virtual & on-demand trainings
- Critical for pediatrician to be a messenger and disseminate

Barriers

- Lack of awareness about importance of screening
- Reimbursement for well-child visits
- Resources (i.e., staff, time)

Needs

- Provider (e.g., HS/EHS, childcare, physician) training
- Peer family advocate/navigator to help increase awareness, identify available resources & connect to services

Step 2

Developmental and Autism Screening

Strengths

- Increased kept appointments due to reduction in other barriers
- Increased collaboration between

Opportunities

- Ability to screen more children in virtual environments while reducing other barriers to screening (e.g., transportation)

Barriers

- Referral hesitancy from families and providers
- Missed appointments/visits

Needs

- Referral coordination and simplification among programs/systems
- Resources (i.e., staffing, funding, technology, online tools)

Step 3

Referral for Services

Strengths

- Programs/systems assemble work groups with a history of collaboration

Opportunities

- Bring programs/systems together to minimize duplication of services and provide coordinated services

Barriers

- Staff/provider capacity
- Timeliness of referrals for receipts of services
- Service deserts
- Limited resources to

Needs

- Increased access and better-quality data on the early identification process
- Provider technical assistance to support families with health appointments

Step 4

Receipt of Services

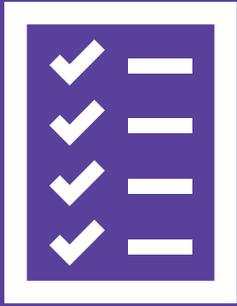
Strengths

- Innovative and creative ways of providing services

Opportunities

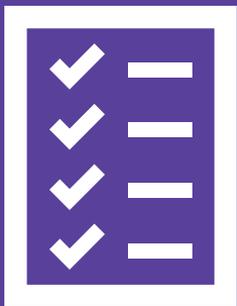
- More comprehensive services provided to families (e.g., mental health supports)

Summary

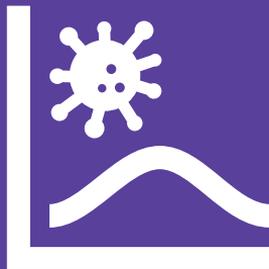


High engagement in each of the 4 steps of early identification

Summary

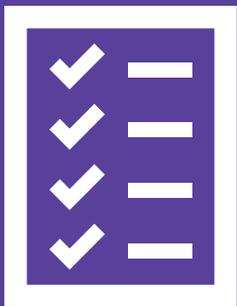


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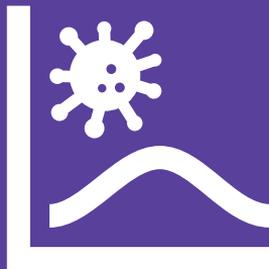


Respondents reported COVID-19 has **highly impacted** each of 4 steps of early identification

Summary



High engagement in each of the 4 steps of early identification



Respondents reported COVID-19 has **highly impacted** each of 4 steps of early identification



Common **barriers, needs, strengths, and opportunities** identified across the 4 steps of early identification

Key Program Contacts

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Thank you!



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