Measuring Up 2: Developmental Delay (MU2:DD) – Phase I Activity Summary Synthesis

Background

In 2023, within the larger Measuring Up project, Child Trends began a new study: *Measuring Up 2 – Examining Policy Factors Related to Prevalence of Infant-Toddler Development Delay (MU2:DD)*. This work is focused on examining risk and protective factors associated with prevalence of developmental delay, as well as specific policies, programs, and practices that exist to prevent or address developmental delay. Specifically, the Collaborative is exploring state variability in referrals, screenings, and service uptake among children experiencing developmental delay, hoping to discover how to promote maximum positive development among children who do not meet developmental milestones. As part of this work, we aim to identify systemic, policy, or programmatic achievements that may mitigate racial and ethnic inequities related to identifying and serving all children experiencing developmental delay. We also hope to identify success stories that make connections between effective policies, programs, and practices—with evidence of effects on the prevalence of positive developmental outcomes for very young children—so that we may amplify their strategies for others to replicate.

Work Completed to Date

Child Trends completed *MU2:DD Phase I – Exploration* activities between April 2023 and December 2024. These initial stages of the work involved a programmatic and data source scan and two expert convenings to inform development of a plan for further in-depth study of this issue. The following activities and deliverables were completed. Internal project deliverables named in endnotes are available upon request.

Activity 1a: Programmatic and data source scan summary memo

In 2023, the Measuring Up 2: Developmental Delay team generated a memo[i] and a presentation[ii] that summarized findings from our initial scan of data sources about developmental delay as well as policies that can potentially affect the prevalence metrics or support services available for developmental delay at the state level for children prenatally up to age three. We identified 21 different nationally representative data sources that included one or more measures pertaining to early childhood developmental delay and disability. We also noted significant variation in policies linked to identifying and serving developmental delay in infants and toddlers.

Activity 1b-1: Two, 2-hour expert convenings

Following the conclusion of the initial data landscape scan (Activity 1a), our team convened a total of 10 experts on infant and toddler developmental delay and disability. The goal of the convenings was to fill gaps in our knowledge and bring together a range of perspectives on Individuals with Disabilities Education Act (IDEA) Part C[1] policy, data, and practice. Participants had a wide range of expertise and included researchers, practitioners, data experts, policy experts, and advocates representing families with children experiencing developmental delay.

Child Trends hosted two virtual convenings, one with research and data experts on November 29th, 2023, and another with practitioners, policy experts, and family advocates on December 15th, 2023. Along with the Child Trends project team, Ami Klin and Lisa Wiggins from the Collaborative joined both convenings. A discussion guide, run of show plan, and PowerPoint deck were prepared to guide the events.[iii] Details about participants and key takeaways were summarized as part of Activity 1b-3 (see below).

Combined with feedback from members of the Collaborative, we gathered further guidance from these experts on the completeness of our literature and data landscape scan, as well as the feasibility of our potential research questions. Specifically, we explored whether the policies and data sources we identified would be sufficient to examine state variation in developmental delay prevalence, screening, or service receipt, and which data sources or policy factors might be the most valuable to explore.

Activity 1b-2: Expert convening summary

Several themes emerged from the 2023 convenings. Specific expert insights included the following:

- States use different measures in early intervention screenings and have different thresholds for what is required to establish eligibility for services.
- Given these differences across states, state-level data on early intervention activities or outcomes cannot be reliably compared, leaving only national data sources for researchers to use.
- Families need better tools and more support from service providers to help them understand and enhance their child's development.
- It is difficult for providers and policymakers to effectively govern and administer well-intentioned but often siloed programs and services (i.e., those that operate independently and tend not to share information).
- Policymakers need more information and better data so they can make informed decisions to support the efficacy and accessibility of early intervention.
- Long waitlists, high workforce turnover, and low pay all impact the efficacy of the early intervention workforce.

In-depth findings were reported in a July 2024 memo.[iv] Expert input helped shape next steps on the project.

---

[1] Part C of the Individuals with Disabilities Education Act authorizes the early intervention program which provides services for eligible children birth through age two with developmental delay or disability.

Activity 1b-3: Data set review high level summary

In 2024, based on the themes and priorities that emerged from discussions with experts (Activity 1b-1), our team revisited the data sources from the 2023 landscape scan memo to identify data sources best suited to help us address identified priorities. We generated a new memo[v] which briefly summarizes key themes from the convenings and describes in more depth the two data sources included in our original landscape scan: the National Survey of Children's Health (NSCH) and IDEA Section 618 data. We anticipate using these data sources to answer research questions identified for the next phase of this work. Additionally, after we published the new memo, the Collaborative also identified a gap in our understanding of Medicaid payer policies and other features of Part C financing. In late fall 2024, our team also identified relevant sources of data including state-level Medicaid financial data, and features of state Medicaid plans that we will incorporate into the next phase of this work.

Activity 1b-4: Research approach summary

In fall of 2024, we generated a high-level summary of exploratory phase activities completed for MU2:DD; research questions and hypotheses developed by the Collaborative; and various research approaches considered by the Collaborative, initially tested by Child Trends, and discussed with subject matter experts.[vi] The aim of the summary was to articulate options for studying the topic of developmental delay and early intervention which the Collaborative may elect to pursue during future phases of the work, in addition to a potential order in which they should happen. It also offered pros and cons for all options and recommendations for the Collaborative to consider. Ultimately, we proposed five options, including:
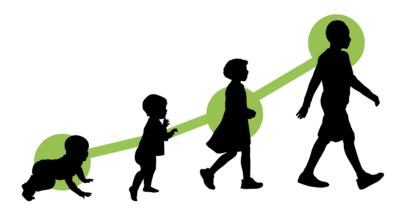
1. **Option 1:** Comparing variation in state compliance with the Early Periodic Screening, Diagnostic, and Treatment Medicaid benefit for infants and toddlers over time.

2. **Option 2:** Examine which changes in states' IDEA Part C policies and practices increase the rate of children receiving developmental delay services.

3. **Option 3:** Testing what state-level policies and contextual characteristics are associated with children receiving services for disabilities/special health care needs.

4. **Option 4:** Identifying which states warrant a case study based on their results to questions 1-3.

5. **Option 5:** Investigating how state leaders, providers, and families are experiencing early intervention and early and periodic screening, diagnostic, and treatment (EPSDT) services.

This work will address a multitude of important and complex issues, including a need for more effective early identification practices as well as a better understanding of the services children and families need to access and how they obtain (and pay for) those services. This plan to investigate and carefully consider early intervention data and service systems may lead to additional recommendations and further stages of work.

Next Steps

Activity 1c: Phased research workplan proposal

Our final deliverable for MU2:DD Phase I – Exploration will be a proposal for future work (Phase 2 – Investigation). The proposal will draw from activities selected from the Research Approach Summary (Activity 1.b-4) and will outline key activities and deliverables, as well as associated costs to complete those activities over a three-year span.

[i] "Measuring Up 2, Developmental Delay (MU2:DD): Summary of Data Sources and Policies Under Consideration" (20231206 MU DD landscape memo _final for Collaborative.pdf)

[ii] MU2DD Collaborative Meeting 9.28.23 (a PDF of PowerPoint Slides)

[iii] "Measuring Up 2: Developmental Delay Policy Convening" (20231215 Convening PPT.pdf)

[iv] "Measuring Up Phase 2: Developmental Delay (MU2:DD): Expert Convening Summary" (Expert Convening Memo_for Collaborative.pdf)

[v] "Measuring Up Phase 2: Developmental Delay (MU2:DD): Review of Datasets Under Consideration" (20240708 Dataset Review Summary_for Collaborative.pdf)

[vi] "Measuring Up 2, Developmental Delay (MU2:DD): Research Approach Summary" (20241210)