SUPPORTING CHILDREN WITH DISABILITIES & DEVELOPMENTAL DELAYS

Meeting Minutes

August 19, 2025 12:00-1:00 p.m.

Agenda:

Welcome, Connector, and Context	10 minutes
Data & Metrics	10 minutes
Survey Results	10 minutes
Discuss Data, Metrics, & Survey Results	20 minutes
Family Portraits Discussion	5 minutes
Public comment & next steps	5 minutes

Workgroup Participants:

Present	Name	Present	Name
	Africa Anderson		Senator Adriane Johnson
	Mindy Brant	X	Samantha Jolliff
X	Benny Delgado		Laura Lindsey
X	Kristy Doan	X	Theenshina Mayfield
	Debra Draper	X	Janice Moenster
X	Johnna Darragh-Ernst	X	Talibah Moore
X	Karen Heath	X	Kim Nelson
X	Kesha Harris		Beatrice Nichols
	Maura Hirschauer	X	Michelle Olivarez-O'Shea
X	Lakeesha Smith	X	Yesenia Perez
	Sanna Jesse		Lynda Williams

Welcome, Introductions & Context

Erin (meeting facilitator) welcomed everyone to the meeting and provided the agenda for the day, which included data, metrics, and survey results, followed by a brief discussion of Family

Portraits. Erin also reminded everyone of the community agreements developed by the workgroup members. The connector activity asked for members to share one thing they noticed in the Family Portraits that we should think about or discuss more. The workgroup members shared the following things they noticed:

- Culture
- Transportation
- Consider the tone in the Mitchell portrait
- Intersectionality of identities across workgroups
- Transportation
- Pediatricians are very important within Early Intervention and I don't think we bring them into the fold enough.
- Peer to peer support
- Families had access to things but what was missing for them is full wraparound supports. We think about the children and need to also think about the parents' needs, and determine if we are connecting all the resources available to embrace the family.
- Making sure we are not using micro-aggressions, counter to our equity framework
- The goal is permanency, not adoption; involvement from fathers
- Cultural differences need to be addressed as much as possible. And it would be helpful to know more about the foster children's background to help support the whole family.
- Curious about what services have been offered to the older children.
- The storytelling is powerful but I'm still trying to understand the audience, how these will be used and connection to a strategy.

Erin reminded users that the purpose of the family portraits is internal use at this time, they will be used to evaluate whether proposed innovations will effectively serve ALL Illinois families, and to ensure that family needs are always at the center of decision-making. They are anonymous composites of real families' stories.

Data and Metrics

Guest presenter Aressa Coley from Afton Partners and the facilitator of the Data, Analytics, and Insights (DAI) workgroup shared the following:

- Last year, you all engaged to inform the Data, Analytics, and Insights (DAI) workgroup's commitment statement and key principles.
- The Commitment Statement serves as IDEC's Data North Star: The new Dept of Early Childhood's Data, Analytics, and Insights function will promote a more equitable system that meets the needs of all children and families by sharing actionable data direction with

  - Families
  - Providers and Administrators
- The DAI Workgroup’s Charge for year 2 is defining the universe of data and insights that will be gathered, and will have 3 priorities
  - Advise on priority metrics
  - Inform data and technology design considerations
  - Co-create an infrastructure for equitable, ongoing stakeholder engagement
- The most important part is making sure the data is actually usable, not just for the agency, but also for families and providers.
- The DAI Workgroup has plans for executing 3 phases of work from now til July 2026. The Workgroup will share recommendations with IDEC at the end of each phase (Oct. 2025, Feb. 2026, Jul. 2026).
- The DAI Workgroup relies on the STEP Framework (System Transformation for Equitable Preschools), which is organized into six early childhood system steps essential for access to quality and equitable early childhood experiences:
  - Supply
  - Outreach
  - Enrollment
  - Learning Experiences
  - Transitions
  - Administration

Survey Results

Guest presenter Beza Bulega from Afton Partners, another Data, Analytics, and Insights (DAI) workgroup facilitator, shared the following:

- The DAI Workgroup had conversations last November-December and completed the survey that we also invited all of you to complete. The workgroup identified which questions they thought were most essential:
  - Does existing supply meet the needs of families from priority populations?
  - Do children from priority populations have access to the developmental supports they need?
  - Are children from priority populations reaching developmental milestones when transitioning to kindergarten?
  - Are there funding mechanisms to support equitable experiences for children, families, and workforce members?

- Members of the Supporting Children with Disabilities and Developmental Delays workgroup also took the survey and prioritized 7 questions, including the four above, plus
    - Do eligibility processes allow families from priority populations to attend programs they want?
    - Are children from priority populations enrolled proportionate, less than or higher than their representation in the community?
    - Do workforce members receive training in supporting the needs of children from priority populations and families?

Discussion:

- A member asked for clarification around the priority populations to consider for this survey.
    - The DAI workgroup looked at multiple populations, but your workgroup is focused on families with children with disabilities or developmental delays.
- A member had a suggestion around specificity. They noted that the essential questions are at a higher level of specificity than the priority metrics themselves. There are more layers of data points that we can collect and develop metrics to determine if we have adequate understandings of, for example, the learning experience.
- Another member agreed with questions about the specificity. They noted that it was hard to decide in the survey because of how broad and high level it was. Something they saw about attendance begged the question of what are the barriers that are preventing families from attending? It didn't feel right to frame it this way because it seemed like a problem coming from families when in fact it's caused by these barriers. They expressed that they weren't sure we could gather data needed, so just did the best they could with the survey, had a lot of questions about it.
- Another member asked whether they could clarify who participated in the survey—were respondents focused on young children with disabilities and delays and asked if it will be shared more broadly. They also offered a minor suggestion – for EQ16—you may want to add transition to PreK for the infants and toddlers who receive EI and/or are in infant/toddler care and learning programs.
- When talking about eligibility processes, a member wasn't certain if it was income based, disability-based, or something else and felt it needs clarifying.

Members were prompted to consider what data from the portraits would be important to collect to represent these families' stories.

- One individual spoke about working in Child Find and part of that role is to look for language differences or needs for a speech pathologist. In doing this, they consider the cultural norm the family anticipates for this child. These norms are not the same across

all cultures and nations. They asked: how are we capturing data that captures how the families are interpreting their children's experiences? When working with families, they often ask, 'what brings those children joy?' and it would probably be different for these two families. If I know the answers to that, they can teach them and help them move toward that.
- A member was looking at the Amin family with hearing loss, and didn't pass the test and was referred but there were cultural differences. Their wondering or hope is that Ages and Stages had been done more frequently than prior to the 18 month visit when it was once again noticed and referred. Is there a way to collect data on the feedback loop? To me, newborn to 18 month is a lot of development time missed. It seemed like the data points were there, the missing piece was the referral follow-up. Why at subsequent visits didn't they follow up? We need to look more closely at how the systems are connected and the pediatricians' understanding of the need for that follow-up. I assume a language barrier was part of that. I worry that there isn't an automatic feedback loop.
- One member was thinking about how data can provide information to schools, families, providers, and specialists about what the child's needs are AND it can also show where there are gaps in services, and who hasn't received services for their needs.

Public Comments

- Available in Public Comment Padlet below

Padlet Comments available at links below:

For workgroup members- https://padlet.com/erin674/supporting-children-with-disabilities-developmental-delays-3p26qae2e5de0qnp

For members of the public- https://padlet.com/erin674/supporting-children-with-disabilities-developmental-delays-p-u2ot2xuzjdg4ydv0

Next Steps

- Future meetings: Tuesdays, noon-1pm (9/23, 10/28, 11/18, 12/16)
- Complete the feedback survey that will be sent out after our meeting