Early Childhood Health Equity Landscape Project

USE OF DATA AND MEASUREMENT IN CROSS-SECTOR EARLY CHILDHOOD HEALTH EQUITY INITIATIVES

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OVERVIEW

This brief presents lessons about the use of data and measurement in cross-sector early childhood health equity initiatives, derived from interviews with five community or state initiative representatives and six representatives from multi-site networks that support local efforts. Part of a larger project entitled the **Early Childhood Health Equity Landscape Project (ECHE)**, this brief – and several companion briefs – aim to highlight promising strategies for addressing key issues such as sustainability, data use, state and local relationships, cross-sector partnerships, and operationalizing health equity within the context of early childhood health equity initiatives. Key findings of this brief identify strategies that these initiatives found to support the use of data and measurement to document progress and improve the impact of their work. Strategies included: community engagement, development of data use agreements, involvement of data experts, and re-thinking strategies for data disaggregation. We conclude with considerations for funders with regard to data and measurement.

Early Childhood Health Equity Landscape Project

Early Childhood Health Equity (ECHE) work seeks to strengthen early childhood systems to support healthy child development and reduce health inequities and disparities that can have a lifelong impact.

In an effort to understand how ECHE work is carried out at the local, state, and national levels, the **ECHE Landscape Project**, a joint venture of the National Institute for Children's Health Quality (NICHQ) and Child Trends and funded by the Robert Wood Johnson Foundation, gathered and analyzed information on cross-sector initiatives promoting early childhood health equity through the **ECHE Landscape Survey.**

To provide context to the ECHE Survey, the ECHE Landscape Project team has also held conversations with ECHE initiatives to inform a series of spotlight briefs on the topics of health equity, measuring and reporting progress and impact, sustainability, cross-sector partnerships, and state-local collaborations. The information from the landscape survey and series of spotlight briefs is intended to support innovation across sectors to advance health equity for young children.

NICHQ
National Institute for Children's Health Quality

EARLY CHILDHOOD
Health Equity Landscape
Learning from Existing & Emerging Initiatives

Child TRENDS

INTRODUCTION

During the last decade, there has been an increasing understanding of how the social determinants of health (e.g., systemic and environmental challenges such as poverty, poor housing, and poor health care) affect the health and well-being of young children and their families. The multi-faceted nature of these challenges has led many communities and states to build – or expand – initiatives composed of representatives from multiple sectors, disciplines, and systems to address disparities in early experiences and outcomes for young children.

As interest in health disparities (and community-wide solutions to address them) grows, there is a need to better understand what challenges these initiatives face and what strategies communities have used to address those challenges.

This brief addresses the use of data for improvement and accountability. As local initiatives develop and mature, they often struggle to create a set of metrics to track their progress and communicate their impact. They face challenges in developing common agreement around which data to collect, building trust with stakeholders (who may come from organizations or communities that have historically been mistreated by researchers) regarding how data will be used and communicated, and accessing and coordinating data that may be housed in multiple agencies.[1,2,3,4] The findings of this brief highlight approaches around data use and measurement design, collection, analysis, and dissemination.

> **"Health equity** means that everyone has a fair and just opportunity to be as healthy as possible. This requires removing obstacles to health such as poverty, discrimination, and their consequences, including powerlessness and lack of access to good jobs with fair pay, quality education and housing, safe environments, and health care."
>
> – Robert Wood Johnson Foundation

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🔑 Key Findings

> **Engaging and empowering community members enhances the richness of the data and helps ensure that the co-design, data collection, analysis, and reporting reflect the priorities of and will benefit the community**

> **Developing data use agreements with aligned organizations clarifies and enhances goals for shared measurement and data collection**

> **Involving data experts in the work facilitates high-quality data practices and analysis**

> **Re-thinking strategies for data disaggregation is critical for identifying and contextualizing areas of strength and challenge in communities**

💡 Methodology

To better understand the use of data in the context of cross-sector early childhood health equity initiatives, the ECHE Landscape Project Team held virtual conversations with individuals working on early childhood health equity initiatives at a local and national network level. We selected local initiatives based on their responses to the **ECHE Landscape Survey**, a survey of initiatives focusing on health equity for children under eight years of age. In this survey, several initiatives indicated that they had a strong or innovative data and measurement component to their work. From these initiatives, we invited a subset of five initiatives to participate in a dialogue. Our intent was to include initiatives targeting diverse geographies and a mix of urban and rural communities. We also excluded any initiatives that had been interviewed for one of the other companion briefs.

The goal of the five conversations was to understand how data enables initiatives to support their community and advance their work. We asked initiatives to discuss the goals and priorities of their work, outcomes, and metrics they use to track progress toward those goals, and how they report their findings to the public. We also asked initiatives to clearly describe how they track outcomes related to health equity, either implicitly or explicitly.

The ECHE Team also spoke with leaders of five multi-site national networks identified through the survey or by experts in the early childhood systems field. These individuals acted as coordinators (e.g., provided technical assistance or facilitated cross-site learning) across states and/or communities. The representatives participated in a group conversation as well as individual follow-up dialogues. The goal of these conversations was to understand the strategies the networks use to report progress over time, including frameworks used to organize metrics, collect data, and share results. We asked the representatives to describe the types of technical assistance they provide to their local sites and how they build consensus on measures and share data among partners. We also asked representatives to describe their observations about the challenges and strategies of local initiatives related to data use. Because the themes that arose from these conversations aligned with those we identified in our conversations with local initiatives, we have combined the insights of the two groups.

Impact of COVID-19

These conversations took place in the context of the COVID-19 pandemic. Although our interview questions and conversations did not focus on the pandemic, this context may have influenced the way that our interviewees thought about their work. For more information on how cross-sector early childhood health equity initiatives responded to the COVID-19 pandemic, please see the related brief "Cross-Sector Support for Health Equity in Early Childhood During the COVID-19 Pandemic." Further, it is important to note that these findings highlight perspectives of a small number of experts. While their experiences are important, they represent only a starting point for further in-depth inquiry.
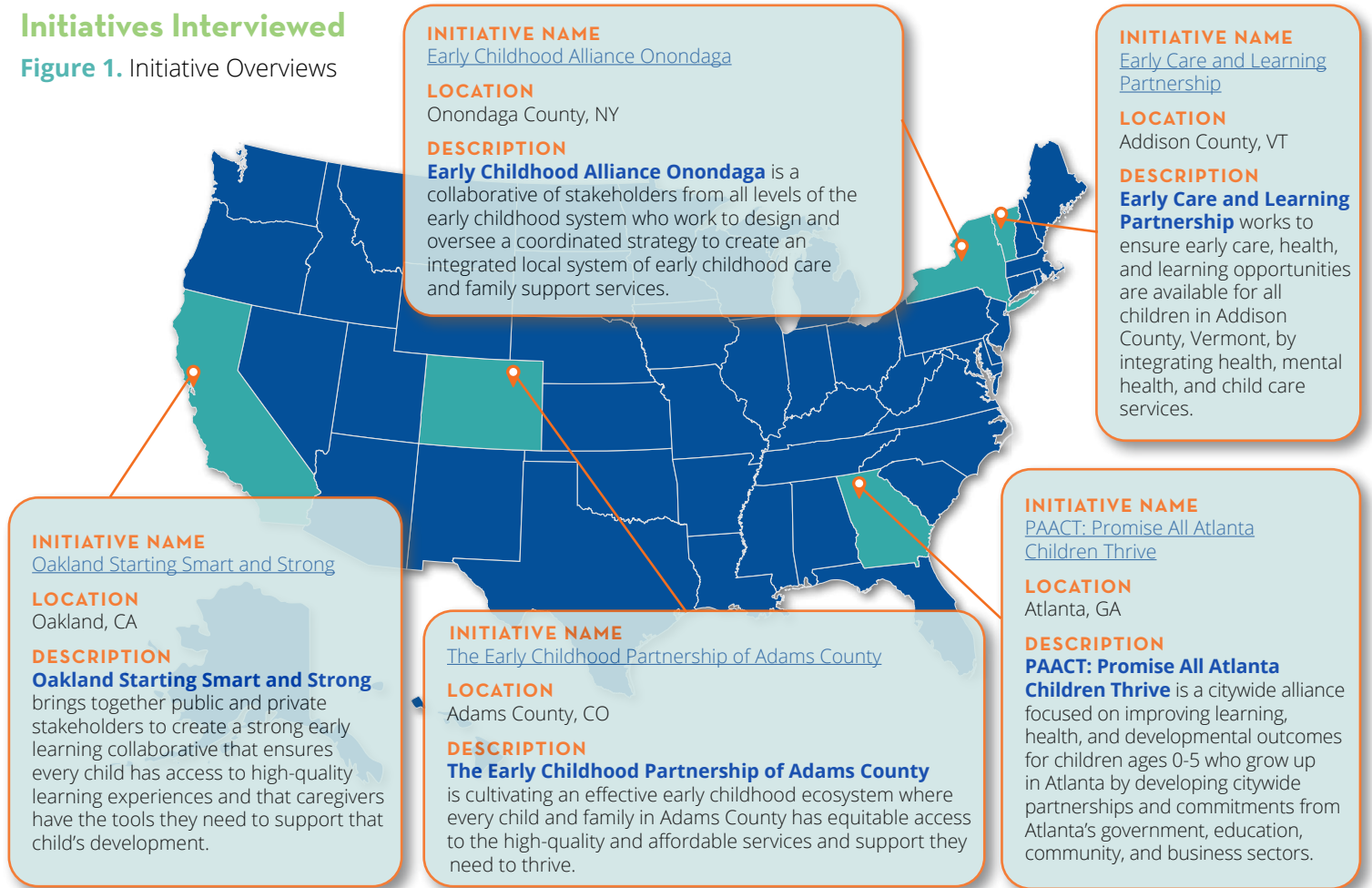
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Initiatives Interviewed

Figure 1. Initiative Overviews

INITIATIVE NAME
Early Childhood Alliance Onondaga

LOCATION
Onondaga County, NY

DESCRIPTION
Early Childhood Alliance Onondaga is a collaborative of stakeholders from all levels of the early childhood system who work to design and oversee a coordinated strategy to create an integrated local system of early childhood care and family support services.

INITIATIVE NAME
Early Care and Learning Partnership

LOCATION
Addison County, VT

DESCRIPTION
Early Care and Learning Partnership works to ensure early care, health, and learning opportunities are available for all children in Addison County, Vermont, by integrating health, mental health, and child care services.

INITIATIVE NAME
Oakland Starting Smart and Strong

LOCATION
Oakland, CA

DESCRIPTION
Oakland Starting Smart and Strong brings together public and private stakeholders to create a strong early learning collaborative that ensures every child has access to high-quality learning experiences and that caregivers have the tools they need to support that child's development.

INITIATIVE NAME
The Early Childhood Partnership of Adams County

LOCATION
Adams County, CO

DESCRIPTION
The Early Childhood Partnership of Adams County is cultivating an effective early childhood ecosystem where every child and family in Adams County has equitable access to the high-quality and affordable services and support they need to thrive.

INITIATIVE NAME
PAACT: Promise All Atlanta Children Thrive

LOCATION
Atlanta, GA

DESCRIPTION
PAACT: Promise All Atlanta Children Thrive is a citywide alliance focused on improving learning, health, and developmental outcomes for children ages 0-5 who grow up in Atlanta by developing citywide partnerships and commitments from Atlanta's government, education, community, and business sectors.

Networks of Initiatives

All Children Thrive (ACT), Transforming Early Childhood Community Systems (TECCS)	Multi-state	**TECCS** is a national initiative catalyzing community-wide improvements in the developmental outcomes of young children across the country
Early Childhood Comprehensive Systems Collaborative Improvement and Innovation Network (ECCS CoIIN)	Multi-state	**ECCS CoIIN** is a multiyear initiative to improve early childhood service systems in 12 states to increase age-appropriate developmental skills among 3-year-old children and reduce developmental disparities
The Early Childhood Learning and Innovation Network for Communities (EC-LINC)	Multi-state	**EC-LINC** is a learning and innovation network of local communities dedicated to bringing together a mix of services, supports, policies, and practices that help all young children and their families thrive—locally and across the nation
StriveTogether	Multi-state	**StriveTogether** is a national network of local communities striving to achieve racial equity and economic mobility by helping communities transform systems and support equitable outcomes for every child, from cradle to career
Vital Village Networks of Opportunity for Child Wellbeing (NOW)	Multi-state (MA)	**Vital Village Networks (VVN)** builds the capacity of communities to optimize child well-being and advance equity through collaboration, research, data-sharing, training, leadership development, and advocacy. **Networks of Opportunity for Child Wellbeing (NOW)** is a national initiative of Vital Village Networks of Opportunity for Childhood Wellbeing

STRATEGIES AND LESSONS LEARNED

The initiative representatives with whom we spoke revealed strategies to build a measurement plan and begin to address challenges in their communities. The key strategies and lessons which promote success in data and measurement include engaging and empowering community members, developing data use agreements with aligned partners, integrating data experts in the work, and rethinking traditional approaches to disaggregating data.

Engage and Empower Community Members

Initiative representatives we spoke with **highlighted the importance of forming authentic relationships with community members early and cultivating those relationships so that they grow throughout the life of the initiative and beyond.** One approach that initiatives used to form these relationships was to identify and engage local champions in the community, who helped to strengthen bonds and build trust between the community and the initiative staff and partners.

When initiatives increase their focus on equity and bring community members "to the table," they have the potential to address historical mistrust of research in some communities and change the dynamic around data. The initiatives we spoke with shared strategies that extend beyond the traditional, more transactional ways initiatives have engaged communities around data. By engaging community members more deeply, initiative staff were able to navigate through the sometimes-difficult waters when trying to both acknowledge community challenges while maintaining a strengths-based lens that reflects the positive capacities within the community.

> "I think a lot of it is just relationships. Trust goes a long way. And people understanding how data is going to be used and that it is not going to be used to hurt them or as a weapon."
>
> — Heidi Black,
>   StriveTogether

Community Involvement in Data Design and Collection

Some initiatives encourage community members to take ownership of the data by inviting them to participate in the design and implementation of data collection efforts. For example, one StriveTogether site gives ownership to parents to administer and monitor the results of the Ages and Stages Questionnaire (ASQ),[5] which provides insights on a child's development. They were testing ways to increase parent administration of the ASQ. This work started in home visiting programs and has now scaled to pediatricians' offices, child care centers, and the school district through the inclusion of the ASQ in kindergarten registration packets. They are currently looking to partner with public housing and other key players in the early childhood sector to further expand these efforts. The community tries different approaches and reports learnings to the StriveTogether network.

Data partners of **StriveTogether**, in turn, share real-time findings with the community, which enables them to engage on a deeper level and use the data to inform future plans. Most local StriveTogether partnerships have a dedicated data person or team. The purpose of the data work is to track and monitor outcome-level data (e.g., kindergarten readiness, 3rd grade reading). The data is disaggregated by race to support improvement teams as they work to implement strategies to improve the system for children and families, including Black, Indigenous, Latinx, and Asian children and families or children and families experiencing poverty. Other StriveTogether partnerships engage the community around different outcomes, and work flows through various mechanisms including advisory councils, board positions, and alongside partnerships to implement strategies. In this way, community members are actively engaged in the initiative and motivated to make progress.

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Engagement of Community in Data Analysis, Reporting, and Dissemination

Involving community members in the interpretation and analysis of data can further build trust, self-efficacy, and a sense of ownership. Initiatives can work with the community to prioritize the data that the community sees as the most helpful.

In several of the multi-site initiatives, national partners provide technical assistance to communities to enable them to collect, analyze, and report on their own data. **Vital Village Networks (VVN)** hosts national webinars, and in-person trainings to help partners adopt and implement equity-based data strategies. This national process is mirrored at the local level. Diana Rivera, Program Manager at VVN, shared that they codesigned data stories and maps with their local sites based on indicators prioritized by the community.

Thoughtful communication is important to ensure data are accurate and reflect the community from a strengths-based perspective. Several initiatives frame the data within the context of a community using a strengths-based approach highlighting resiliency, rather than trying to compare across communities. Leila Espinosa, Project Director at **All Children Thrive (ACT)**, **Transforming Early Childhood Community Systems (TECCS)**, is conscientious about how data, especially when disaggregated by race and ethnicity, can be misused or misinterpreted. She believes that sites should learn how to facilitate and lead meaningful data conversations so that the community feels empowered that the data is owned by them and they can create the narrative around it. Data interpretation and solutions development should involve those most impacted.

> "We had a great epiphany around the kindergarten readiness question and flipping it from, 'Are children ready for school?' to 'Are schools and communities ready for children?' And I think that is always at the center of how we're looking at data."
>
> — Priya Jagannathan,
>   Oakland Starting Smart and Strong

> "The harmful effects of racism can be measured at the population level."
>
> — Leila Espinosa,
>   All Children Thrive, Transforming Early Childhood Community Systems

Espinosa shared details about how ACT, TECCS provides technical assistance for sites to effectively understand, discuss, and present data through a three-part approach to preventing the misuse and misinterpretation of the data, especially around race/ethnicity. Their approach starts with intentional framing of the data, along with a deliberate analytical approach, and finally, a framework for interpretation. ACT, TECCS acknowledges the historical misuse of data to draw unjust conclusions about people, and that data on equity, racism, and violence has the potential to cause trauma. Through their analysis, they take explicit anti-racist approaches, including graphing equity gaps by comparing individual groups to the average (means) across all racial/ethnic groups, instead of defaulting to White as the standard or norm. ACT, TECCS reframes the conversation around data to be reflective of the systems impact on populations as opposed to inherent characteristics of the populations.

To better tell the community's story, many multi-site initiatives collect qualitative data along with quantitative data. Qualitative data allows initiatives to communicate strengths and contextualize quantitative data with people's lived experiences. This also provides the community an opportunity to set their own narrative. Data can be more persuasive in the context of stories. Pairing quantitative and qualitative data can be particularly effective and compelling.

Data Justice

In at least one of the sites, **Oakland Starting Smart and Strong**, the initiative partners incorporate a *data justice* lens in their work.[6] Like other initiatives, Oakland Starting Smart and Strong has rejected the deficit lens and, instead, employed a strengths-based lens to all data reporting. They don't stop at using a strengths-based lens – Oakland Starting Smart and Strong recognizes their community advisors as experts. They remind their community that the data does not define them, but that they can use it to advocate for their needs. Community experts or advisors are involved in conversations about how they would like to receive their data, whether it be in a report format or other presentation style. Oakland Starting Smart and Strong worked with Oakland Unified School District and community partners to provide input on the creation of an interactive data dashboard for the Early Development Instrument (EDI)[7], and is currently creating videos with parents on their knowledge about their neighborhoods and what they find useful about the EDI. As a result, Oakland Starting Smart and Strong has been able to maintain a robust network of community partners.

> **DATA JUSTICE:**
>
> Applying fairness in the way people are made visible, represented, and treated as result of their production of digital data. [7]

> **LANGUAGE JUSTICE:**
>
> The right everyone has to communicate in the language one feels most comfortable.[8]

Another initiative, **Vital Village Networks (VVN)**, takes a *language justice*[8] approach to ensure that participation is equitable and that local leaders in the network can fully participate in the data co-design, implementation process, and dissemination. They strive to respond to language justice needs that emerge from participating partners, offering simultaneous interpretation during virtual meetings and sessions, as well as translated information in both English and Spanish for selected materials, so that their constituents have equal access to information.

Developing Data Use Agreements with Aligned Partners

Building partnerships with other organizations with similar missions has many benefits in this work, including data sharing. It is easier to focus on outcomes and impact when there is a coordinated effort to standardize and share data. Memoranda of Understanding (MOU) and data use agreements help make this possible. **The Early Childhood Partnership of Adams County** is working to translate outputs and outcomes into impact at the systems level. The initiative encourages shared accountability by requesting data from their partners. For example, when the initiative promotes a home visiting program, they follow up with community partners to learn about how their work has affected the number of new referrals. **All Children Thrive, Transforming Early Childhood Community Systems (ACT, TECCS)** also uses MOUs to coordinate their data efforts across local sites. Early in their work they did not have formal agreements and felt limited by the challenges of using different record systems and the understandably strict regulations to protect privacy. Now ACT, TECCS is part of a movement to support interoperability and integration of data systems across the life course.

By having a formal data agreement, initiatives can understand the larger environment in which they operate and gain a greater understanding of their contribution to the early childhood system. However, it is not always feasible for partners to change how they collect and report data because some may have reporting requirements specified in their grants. In this case, initiatives must work with the information they have available.

Involve Data Experts Who Value Participatory Community Data Engagement

All the initiatives we interviewed for this brief had data experts on hand, either working directly for the initiatives or embedded in a partner organization. These experts can ensure that the right questions are being asked, help analyze the data, and, along with the community members and partners, provide input on how it is presented. **The Early Childhood Alliance of Onondaga** planned to hire an in-house data analyst but instead partnered with Syracuse University for data analysis. **Vital Village Networks (VVN)** takes a multi-pronged approach with community data engagement expertise with their staff, as well as external evaluators who embrace participatory strategies that invite community residents to partner in the development, implementation, and interpretation of evaluation tools. Internally, VVN provides technical assistance for their community sites to conduct a self-driven data project and to collect data on their individual programmatic activities. Quarterly, the external evaluators collect information from local implementation sites about partnerships and cross-sector collaboration, adapting the Wilder Collaboration Factors Index Survey[9] and allowing local sites to design customized, site-specific questions as well. This data is used to support the design and capacity-building of the technical assistance VVN provides.

Rethink Data Disaggregation

Initiatives can deepen their understanding and engagement of the communities they serve when they move beyond disaggregating data solely by race and ethnicity. Most initiatives we spoke with disaggregate data by some combination of race, ethnicity, and zip code. Disaggregating data allows initiatives and their constituents to examine inequities that could be hidden by studying only population-level data. Even then, there are some populations (e.g., migrant workers) who are not represented by disaggregating data by race and ethnicity. Also, race and ethnicity data in isolation does not always tell a complete story. When presenting data, initiatives should take care to describe the context for inequities so that the outcomes can also be properly contextualized. Initiatives may also consider putting explicit attention on populations who may be overlooked by using standard data categories. Initiatives should invest time in identifying metrics that reflect the populations they wish to serve. When initiatives capture robust and refined data, they can tailor interventions to specific populations.

In some cases, it may be challenging to come to meaningful conclusions in communities due to small numbers in some racial groups. However, a skilled statistician can help address this issue. For example, the Center for the Study of Social Policy (CSSP) advises EC-LINC communities to group data in 3-5 year birth cohorts to allow for data disaggregation and analysis for differences among subgroups. Qualitative research is another way to gather data on the experiences of families in a particular racial/ethnic or other group where there may be small numbers.

CONSIDERATIONS FOR FUNDERS

Our interviews identified several ways that funders can better support initiatives' use of data for improvement. Underlying the challenge of demonstrating impact at the systems level is a call for funders to recognize the time and resources required to make and measure lasting change. We suggest that funders consider these issues when planning funding opportunities:

> **Ensuring sufficient resources for data-related activities**

> **Providing time at the start of the project period to plan for data collection and to build partnerships**

> **Allowing for flexibility in measurement**

> **Being clear and consistent around measurement expectations**

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Resources for Data-Related Activities

Multiple initiatives noted that that often there is a data requirement, but no allocation of funds to support staff leading and doing this work. **As a result, data activities (designing, collecting, analyzing and reporting) become more challenging, and data is either missing or not helpful to informing the work or reflecting progress.** When planning funding opportunities, it is important for funders to include financial support for:

> **Time and resources in building and maintaining partnerships to facilitate data sharing and integration**

> **Engaging the community and building their capacity in data-related work**

> **Supporting data collection tools, analysis, and reporting**

Time to Plan for Data Collection and Partnerships

Financial resources for data collection and partnerships are not sufficient to support communities. Trust is critical to communities' use of data and measures, yet trust takes time to develop. Initiatives need the space and support to nurture these relationships early in the life of an initiative. **Vital Village Networks (VVN)** shared that they planned for intentional time at the beginning of the NOW initiative for partners to define and co-design a shared metric of child well-being that they would all collect, track, and share through their Child Wellbeing Tracker (CWT).[10] This investment cultivated buy-in and encouraged shared value and ownership of data collection and shared measurement. It also provided an opportunity to build shared understanding due to the different levels of interest, familiarity, and capacity around data across sites. **VVN also made the case for data collection by emboldening their community partners to see it as a way to build their own capacity, and in turn, tell effective stories about their progress and impact.** Eventually, VVN gave community members ownership of their data. Laying the foundation for strong partnerships takes time and does not always yield immediate results. This work should be valued as integral to systems change.

Alignment and Flexibility in Measurement Requirements

A key challenge noted by several participants pertains to grant requirements for data reporting. Funders prioritize reports on the number of services received by community members or outcomes of those services. But, as discussed, cross-sector collaborative initiatives take time to develop trust and build a shared vision for the use of measurement and data. Moreover, the sort of systems-level changes that these initiatives prioritize take time and are likely to precede service or outcomes improvements. **Measurement requirements should mirror the expected timing of changes, beginning with documentation of coalition building before moving to service provision.**

Funders should also consider how their data and reporting requirements can influence the community's efforts to promote greater coordination between early care and education and health systems. These initiatives may have multiple funders, all of which ask for different data. By remaining flexible in their data requirements, funders can provide space for communities to determine their own metrics and avoid the inefficiencies from navigating multiple performance reporting systems. Several national networks **(ECCS CoIIN, Vital Village Networks, and EC-LINC)** encouraged communities to co-design the measures to ensure that they would not be too burdensome and would be helpful to them in informing their work.

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SUMMARY

Through conversations with 10 local and multi-site initiative representatives, the Early Childhood Health Equity Landscape Project Team has identified key strategies related to data and measurement. Strategies include actively engaging community members throughout the process, partnering with allied organizations within and across sectors, involving data experts from the beginning, and re-thinking strategies for data disaggregation. Included are reflections which funders can consider. It is the ECHE Team's hope that this brief illuminates the experiences of the early childhood initiatives of today and informs the project opportunities of tomorrow. These findings highlight perspectives supported by conversations with a small representation of leaders in a small number of initiatives. In-depth research is needed on more initiatives to build out and solidify the strategies.

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