

Locking Arms to Unlock Potential

Recommendations to Strengthen
Services for Black/African American
Children with Developmental Needs
in Los Angeles County

Help Me Grow Los Angeles Equity Work Group

September 2025





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Background

In the U.S., approximately one in six children ages 3 to 17 has one or more developmental delays or disabilities. Timely access to developmental screening and intervention is critical for ensuring each child reaches their full potential. However, deeply rooted structural issues and systemic racism — manifested in patterns of treatment such as neglect, trivialization of concerns, and bias² — continue to remain barriers for Black/African American children and families, obstructing access to these critical health services.

In California, two primary service systems — referred to throughout this report as early identification and intervention (EII) systems — support families of children ages birth to 3 with developmental delays or disabilities: regional centers, which support coordination and delivery of services for individuals with developmental disabilities, and the healthcare system, which provides developmental screenings and linkage to services. Available data highlight disparities, particularly for Black/African American families, who experience lower service quality, reduced access and delayed eligibility determinations, despite existing efforts to reduce disparities (see next section). For example:

• **Early Intervention:** Statewide, Black/African American children receive fewer services, as indicated in their Individualized Family Service Plans, compared to white, Hispanic and Asian children.³

¹ Centers for Disease Control and Prevention. (2024). *Developmental disability basics*. https://www.cdc.gov/child-developmental-disability-basics.html.

² Batz, R., & Yadav, A. (2024). Parents' experiences navigating early intervention and early childhood special education services: A qualitative metasynthesis. *Journal of Early Intervention*, 46(1), 19–38.

Dababnah, S., Shaia, W. E., Campion, K., & Nichols, H. M. (2018). "We had to keep pushing": Caregivers' perspectives on autism screening and referral practices of Black children in primary care. *Intellectual and Developmental Disabilities*, *56*(5), 321–336.

Zuckerman, K. E., Mattox, K. M., Sinche, B. K., Blaschke, G. S., & Bethell, C. (2014). Racial, ethnic, and language disparities in early childhood developmental/behavioral evaluations: A narrative review. *Clinical Pediatrics*, 53(7), 619–631. https://doi.org/10.1177/0009922814538491.

Magaña, S., Parish, S. L., Rose, R. A., Timberlake, M., & Swaine, J. G. (2012). Racial and ethnic disparities in quality of health care among children with autism and other developmental disabilities. *Intellectual and Developmental Disabilities*, 50(4), 287–299.

Weitlauf, A. S., Vehorn, A., Miceli, A., Pinnock, T., Dada, Y., Hine, J., & Warren, Z. (2022). Black families' experiences of developmental screening: Review of well-child visits to inform enhanced autism spectrum disorder risk assessment. *Journal of Developmental & Behavioral Pediatrics*, 43(9), 503–510.

Slopen, N., Chang, A. R., Johnson, T. J., Anderson, A. T., Bate, A. M., Clark, S., ... & Heard-Garris, N. (2024). Racial and ethnic inequities in the quality of pediatric care in the USA: A review of quantitative evidence. *The Lancet Child & Adolescent Health*, 8(2), 147–158.

³ California Department of Developmental Services. (2025). *Annual Purchase of Service (POS) reports: Fiscal year* 2023–2024. https://www.dds.ca.gov/rc/purchase-of-service-data/.

- **Quality of Services:** In Los Angeles County, the lowest average monthly spending per child on Early Start services is for Black/African American children.⁴
- **Timely Eligibility Determinations:** Statewide, Black/African American children face more delays in eligibility assessments compared to white children.⁵
- Caregiver Experience: Several studies have found that Black/African American caregivers report lower-quality care when accessing early intervention services and medical care.⁶

Help Me Grow LA (HMG LA) was established in 2018 to address gaps in access to early intervention services and promote awareness of child development. HMG LA connects families with resources and support to promote their children's development. In November 2021, the Los Angeles County Department of Public Health (DPH), HMG LA's organizing entity, in partnership with First 5 Los Angeles (First 5 LA), launched the **HMG LA Equity Work Group** and identified Black/African American families as a priority population. This was based on available data, historical context, COVID-19 impacts and an alignment with existing efforts in L.A. County. The Equity Work Group originally included staff and was later expanded in July 2023 to include community members rooted in the priority population. The HMG LA Equity Work Group then hosted listening sessions conducted by the Westside Infant-Family Network, reaching 36 total participants.

Drawing on listening session findings, available data and the lived experience of work group members, this report presents a series of recommendations to strengthen early intervention systems in L.A. County and beyond to better serve Black/African American families. These recommendations represent the culmination of years of collaboration among HMG LA, community members, and partners.

At a time when equity-centered programs face increased federal challenges, we remain committed to addressing disparities and improving support systems for Black/African American families navigating early intervention services, and hope that these recommendations provide a pathway to do so.

⁴ Lovell, V. (2021, June 16). *Trends in Early Start referrals and participation in Los Angeles County* [Presentation]. California Department of Developmental Services.

⁵ California Department of Developmental Services. (2022). *FY 2020–21 disparity measures*. https://www.dds.ca.gov/wp-content/uploads/2022/05/FY20-21_DisparityMeasures_English.pdf.

⁶ Bailey, D., Scarborough, A., & Hebbeler, K. (2003). *Families' first experiences with early intervention: National Early Intervention Longitudinal Study (NEILS) data report*. U.S. Department of Education.

Cheak-Zamora, N. C., & Thullen, M. (2017). Disparities in quality and access to care for children with developmental disabilities and multiple health conditions. *Maternal and Child Health Journal*, *21*(1), 36–44. Stahmer, A. C., et. al (2019). Caregiver voices: Cross-cultural input on improving access to autism services. *Journal of Racial and Ethnic Health Disparities*, *6*(4), 752–773.

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Experiences of Black/African American Families with Early Identification and Intervention Systems in LA County: Key Findings

As an initial step to identify how EII systems in LA County can better serve Black/African American families, the HMG LA Equity Work Group conducted a series of listening sessions and discussions among members with lived experiences, with the goal of better understanding the experiences of Black/African American families. Key themes are highlighted below, while a full report of findings can be found in the appendix:

1. Limited Awareness and Lack of Culturally Relevant Outreach

Caregivers in listening sessions noted that many families are unaware of available early intervention services for their children, while work group members highlighted that existing outreach is often not culturally relevant and doesn't sufficiently engage grassroots partners rooted in Black/African American communities. In some cases, marketing materials lack representation of Black/African American families and/or tend to include stereotypical imagery.

2. Burden on Families

Parents and caregivers feel solely responsible for navigating early intervention systems and advocating for their child's care, with little system support.

- **3. Parents Look to Primary Care Providers, But Often Don't Get What They Need** Families rely on primary care providers for guidance on early intervention, but often do not receive the necessary information, referrals, or support. Work group members noted that community clinics in particular are where many Black/African American families turn for pediatric care, but many clinics do not conduct developmental screenings or provide necessary referrals.
- **4.** Black/African American families do not feel heard, seen, or respected by providers Black/African American families frequently reported feeling that their concerns were dismissed and that they were treated differently by some providers due to their race, ethnicity and social status. These experiences can disrupt and delay opportunities for early intervention and diagnosis, as well as contribute to a lack of trust in medical and EII service systems.

5. Need for Provider Training and Accountability on Anti-Blackness and Cultural Humility

Work group members emphasized that many medical and EII providers need more training on topics such as anti-Blackness, cultural humility, implicit bias and other relevant topics.

Additionally, even when training is offered, there are often no mechanisms in place for accountability or to track implementation of any changes to measure effectiveness.

6. Importance of Peer Support

Both listening sessions and work group members emphasized the value of being able to connect with other parents and caregivers for shared experiences and support in navigating early intervention systems.

7. Workforce Challenges

Both listening session participants and work group members identified a lack of representation in the EII workforce as a critical barrier to access, both in parent-facing roles (e.g., service coordinators) and in decision-making roles. This was believed to be a contributing factor to the poor quality of care for Black/African American families. Additionally, work group members emphasized the need to address the root causes of high staff turnover at regional centers, causing disruption in care for families.

8. Need for Standardization, Coordination, and Improved Capacity at Regional Centers

Work group members noted the seven L.A. County regional centers could benefit from standardized processes to avoid challenges and reduce confusion for both families and providers. Likely, any standardization efforts would be most effective coming from DDS, for example, in the form of statewide standardized intake protocols and reporting systems. Further, they noted that regional centers need more funding and increased capacity to meet the needs of the community. Addressing these needs can help avoid bias and discrimination in terms of who gets served and improve how outreach — as well as other aspects of services — is conducted.



Existing Work to Engage Black/African American Families and Promote Access in LA County

Following completion of listening sessions, the Equity Work Group additionally sought to understand key efforts already in place in LA County to support Black/African American families in early identification and intervention. Three main methods were used to scan existing efforts: sharing within the Equity Work Group, online searching, and a series of conversations, held by First 5 LA in May-July 2025 with the seven LA County regional centers, covering equity efforts and other topics. While the following list is not exhaustive, it highlights key themes and lays the foundation for Equity Work Group Recommendations presented in the next section.

Regional Center/FRC Equity Efforts and Peer Support Resources

All regional centers described efforts to promote equity, decrease disparities in access to services and offer more peer supports to parents/caregivers of young children, often in partnership with and/or led by their associated family resource centers (FRCs). As part of this larger commitment, all regional centers additionally reported engaging in at least one strategy that specifically focused on Black/African American families. Key strategies included:

- **Partnering with community-based organizations** led by or rooted in Black/African American communities (mentioned by five of seven regional centers/FRCs).
- **Offering support groups** specifically for Black/African American parents/caregivers (mentioned by four of seven regional centers/FRCs, with one regional center having a group specifically for Ethiopian- or Amharic-speaking families).
- Conducting tailored outreach to Black/African American families through
 participation at community events hosted by Black-led organizations and networks,
 events geared primarily toward Black/African American families or the hiring of
 promotores rooted in Black/African American communities (mentioned by four of
 seven regional centers/FRCs).
- **Offering one-on-one peer mentoring** with efforts to match on culture, race or ethnicity, or intentionally recruiting Black/African American parents/caregivers as mentors (mentioned by three of seven regional centers/FRCs).
- Conducting activities to better understand the barriers and lived experiences of Black/African American families, such as tailored listening sessions, focus groups, communities of practice, and family surveys (mentioned by three of seven regional centers/FRCs).
- Including Black/African American families as a priority population for the DDSfunded Community Navigator Program (mentioned by two of seven regional centers/FRCs).
- Forming a specialized unit to reduce inequities in service access (mentioned by two
 of seven regional centers). One unit focused on serving individuals with little to no

Purchase of Service (POS),⁷ a group that predominantly includes Black/African American and Latino families (ages 3+); and one unit is currently expanding to include Black/African American families, as well as monolingual Spanish-, Cantonese-, and Mandarin-speaking families.

- Investing in staff training focused specifically on cultural awareness and humility related to Black/African American families (mentioned by two of seven regional centers/FRCs).
- **Emphasizing the importance of hiring staff with lived experience** in Black/African American/African communities (mentioned by one of seven regional centers/FRCs).

Additional Efforts to Support Black/African American Families in EII

Other relevant statewide and local efforts include (but are not limited to):

- CBO-led supports offered by and for Black/African American families, such as those
 offered by <u>Access Nonprofit Center</u>, <u>Ohana Center</u>, <u>Leap of Faith Nonprofit</u>, <u>WIN Los</u>
 <u>Angeles</u>, and others.
- The DDS state workgroup, which focuses on supporting the needs of Black families
- Special Needs Network's Creating Opportunities for Equity in Early Intervention (CORE) grants, supporting the growth of BIPOC early intervention clinicians.
- Disability Rights Now's report, <u>From Navigation to Transformation: Addressing Inequities in California's Regional Center System Through Community-Led Solutions.</u>
- The launch and growth of the <u>Medi-Cal Community Health Worker (CHW) benefit</u>, which provides culturally relevant health information and supportive services.
- The L.A. County Anti-Racism, Diversity, and Inclusion Initiative (<u>ARDI</u>), which has undertaken several key equity initiatives, such as the <u>State of Black Los Angeles</u> <u>County report</u> and trainings for county employees.
- The African American Home Visiting Engagement Work Group, which seeks to raise consciousness, build trust, and change practices to recruit and support African American home visiting staff and increase African American families in home visiting.
- Health care pipeline programs, such as <u>Charles Drew University's Pathways Programs</u>, which focus on increasing representation of Black/African American and other underrepresented communities in the workforce, particularly in pediatrics and other specialties relevant to early intervention.

⁷ Purchase of Service (POS) refers to the actual purchase of services by the regional center to support an individual with developmental delays or disabilities, based on their individual needs as defined in their Individual Family Service Plan (IFSP) or Individual Program Plan (IPP). POS data is one of the primary data points used by the California Department of Developmental Services to assess disparities. Learn more at https://www.dds.ca.gov/rc/purchase-of-service-data/.

Recommendations for Change

Drawing on the collective learnings and experiences described above, the Equity Work Group developed a series of recommendations intended to help EII systems better serve Black/African American families. These recommendations are summarized in the following table.

Strategy 1: Community and Trust Building	Strategy 2: Education, Training and Policy	Strategy 3: Workforce Development
1.1 Improve pathways for Black/African American families to connect with peer supports through the regional center.* 1.2 Strengthen and expand peer support programs to meet the needs of Black/African American families.*	2.1 Create a training and accountability framework to reduce anti-Blackness and ensure fair and high-quality EII services for Black/African American families. 2.2 Establish an organizational development and culture-change policy that includes mandatory education and actionable strategies to identify and address anti-Blackness. Trainings must be accompanied by this policy so as to ensure meaningful and lasting change. 2.3 Develop and implement restorative racial healing practices, clear protocols, practical resources and dedicated spaces for staff and families to address and heal from racial trauma.*	3.1 Strengthen recruitment of Black/African American employees across the EII services landscape. 3.2 Improve retention of Black/African American employees in EII organizations by supporting employee safety and well-being.

^{*}Rated as top priority by the Equity Work Group (1.1, 1.2, and 2.3)



STRATEGY 1: COMMUNITY AND TRUST BUILDING

Barriers Addressed: Inadequate peer support, lack of awareness and culturally relevant outreach, burden on families, not feeling seen/heard/respected by providers, parents looking to providers but not getting what they need

Potential Implementing Systems: Regional centers and their vendors, healthcare, HMG LA; in collaboration with grassroots organizations and Early Start Family Resource Centers

Recommendations:

- 1.1 Improve pathways for Black/African American families to connect with peer supports through a regional center.
- 1.2 Strengthen and expand peer support programs to meet the needs of Black/African American families.

Among all recommendation areas, work group members assigned the highest priority to expanding and enhancing peer supports available to Black/African American families within relevant early intervention systems. This includes two key strategies:

1.1 Improve pathways for Black/African American families to connect with peer supports through a regional center.

While Early Start Family Resource and Empowerment Centers offer peer support through staff with lived experience, families and community members have shared that it's also important to make this kind of support more available directly at regional centers. In particular, connecting Black/African American parents and caregivers with others who share similar experiences can make the process feel more welcoming and supportive from the very beginning.

One key part of this strategy is **improving current processes so that peer support starts early** — right when families first connect with the regional center. This means working with regional centers to align and strengthen intake procedures across the system, ensuring that Black/African American families are connected with a parent peer at the beginning, not just after eligibility is determined. Peer supporters may include Black/African American parents with experience receiving services or regional center staff with lived experience.

1.2 Strengthen and expand peer support programs to meet the needs of Black/African American families.

This strategy builds on existing efforts and investments in peer support by large public systems — such as the DDS Community Navigator Program and the Medi-Cal Community Health Worker benefit — and calls for a more intentional focus on the unique needs of Black/African American families.

Recommendations for enhancing peer support programs include:

- Reduce barriers to participation by offering flexible, accessible support. Provide
 flexible support options like respite care, transportation and family-friendly
 scheduling to make it easier for families to engage. Ensure supports are culturally
 responsive, informed by community input and widely promoted, to increase
 awareness and equitable utilization.
- Reduce systemic barriers for grassroots organizations to strengthen community-driven support. Build and expand partnerships with trusted, community-rooted organizations—especially those serving Black/African American communities—to grow peer support networks grounded in lived experience and cultural trust. Foster collaboration between philanthropy, community, and early intervention systems by reducing bureaucratic hurdles to funding and contracting, ensuring grassroots organizations have equitable access to resources and opportunities.
- Expand funding for culturally responsive peer support.
 Community partners consistently highlight the strong impact of Cultural Navigator and Promotora programs in increasing access, trust, and engagement across diverse communities. These supports not only benefit individuals and families but also enhance service coordination and resource navigation. We encourage DDS to continue and expand its investment in the Cultural Navigator Program and Service Access and Equity grants to grow culturally responsive peer support.
- Support regional centers to explore and leverage alternative funding streams.

 Resources such as Medi-Cal could be used to increase the availability of Black/African American community health workers and peer supports.

STRATEGY 2: EDUCATION, TRAINING, AND POLICY

Barriers addressed: Need for provider training and accountability on Anti-Blackness and Cultural Humility; Black/African American families do not feel heard, seen, or respected by providers; families looking to providers but not getting what they need

Potential Implementing Systems: Regional centers and vendors, HMG LA, healthcare providers; in partnership with ARDI and content experts/consultants/CBOs rooted in the Black/African American community and topics described

Recommendations:

- 2.1 Create a training and accountability framework to reduce anti-Blackness and ensure fair, high-quality EII services for Black/African American families.
- 2.2 Establish an organizational development and culture-change policy that includes mandatory education and actionable strategies to identify and address anti-Blackness. Training must be accompanied by this policy to ensure meaningful and lasting change.

2.3 Develop and implement restorative racial healing practices, clear protocols, practical resources, and dedicated spaces for staff and families to address and heal from racial trauma.

2.1 Create a training and accountability framework to reduce anti-Blackness and ensure fair, high-quality EII services for Black/African American families.

Listening session participants and work group members have shared that some Black/African American families don't always feel respected or understood when interacting with early intervention and medical providers. One way to strengthen trust and improve care is to ensure all providers receive high-quality, ongoing training that helps them better serve all families.

This strategy focuses on:

- Creating a strong, community-informed training program that includes important topics like cultural humility, anti-Blackness, bias, and systemic racism — developed with input from Black/African American families and professionals.
 - Making the training practical and relevant, with real examples and data from local communities, and using trusted trainers who understand the specific needs of each audience.
 - o **Ensuring the training is standard across systems that provide EII services** by including it in onboarding for new staff and offering it to all staff every year.
 - Key topics covered may include:
 - The historical roots of bias and discrimination, including anti-Blackness, in society and the workplace
 - Recognizing and addressing microaggressions and implicit bias
 - How to speak up and support others when witnessing harmful behavior
 - "Cultural First Aid" simple, respectful ways to build trust and connection with families
- Creating an accountability framework to ensure the training leads to meaningful change. To ensure that learnings from the training above are embedded into practice, health providers, policy makers, philanthropies and other community-based organizations should adopt an accountability framework. This could include:
 - Tools to track progress and improve how trainings are delivered
 - Clear definitions of what success looks like
 - Ongoing evaluation, feedback and transparency
 - Coaching and support for staff to apply what they've learned
 - o Regular convenings to share progress and elevate family voices

2.2 Establish an organizational development and culture-change policy that includes mandatory education and actionable strategies to identify and address anti-Blackness. Training must be accompanied by this policy to ensure meaningful and lasting change.

To drive lasting change, organizations must go beyond individual accountability and **commit to system-wide culture shifts**. This includes a clear policy that mandates anti-Blackness education and outlines actionable steps to address anti-Blackness. Key recommendations for organizations and entities within EII systems include:

Organizational Policies and Practices

- Equip human resources (HR) with the expertise or support needed to address anti-Blackness and racial trauma without causing further harm
 - Strengthen HR capacity and readiness to support employee safety and healing when harm is done; for example, by increasing capacity related to racial trauma and healing and/or by bringing on experts
 - o Implement mandatory, HR-specific training on cultural sensitivity, anti-Blackness and microaggressions
 - Organizational leadership should hold HR accountable for providing safe and inclusive spaces for Black/African American employees
- **Review and revise internal policies** such as dress codes to remove racially biased or race-coded rules (e.g., hair and grooming standards)
- Update performance evaluations:
 - o Use 360-degree feedback, including supervisor reviews by staff
 - o Include racial equity work as a performance metric
 - o Reevaluate the use of merit-based raises, which can reflect systemic bias

Inclusive Meetings and Workspaces

- Ensure meetings are accessible and inclusive, with hybrid options
- Create safe spaces for Black/African American staff, clients and families
- Avoid tokenism include multiple Black/African American voices in discussions whenever possible

Culture Change

- Be intentional with language and publicly commit to change. Employ statements such as "We are decolonizing our workplace practices..." or "We no longer support..." to clearly signal shifts in values and behavior
- 2.3 Develop and implement restorative racial healing practices, clear protocols, practical resources, and dedicated spaces for staff and families to address and heal from racial trauma.

Chronic exposure to racism and its many manifestations has serious health impacts on the mental and physical well-being of Black/African American people. Creating healing spaces to address this trauma is critical to supporting the well-being of Black/African American employees and families and preventing burnout. Organizations can support healing spaces through the following strategies:

- **Invest in safe spaces, activities, resources/tools** that encourage healing, mental well-being and prevention of burnout, especially in response to racial trauma
 - Curate safe healing spaces specifically for Black/African American staff and families
 - Offer dedicated safe spaces and training for allies to reflect, ask questions, learn, and be held accountable for their learning—without placing that burden on Black/African American colleagues
- **Acknowledge previous harm done** by the system to Black/African American people, and commit to healing and culture change going forward
- Establish restorative justice protocols to address when harm is done, and provide acknowledgement, transparency, and a plan of action by leadership
- Welcome and respond to feedback at an organizational level

STRATEGY 3: WORKFORCE DEVELOPMENT

Barriers Addressed: Workforce challenges, lack of culturally relevant outreach, parents do not feel seen/heard/respected by providers

Potential Implementing Systems: Regional centers, healthcare, mental health care, LAUSD, California Children's Services (CCS), DCFS, home visiting; in partnership with the LA County CEO's Office, skilled consultants, grassroots CBOs

Recommendations:

- 3.1 Strengthen recruitment of Black/African American employees across the EII services landscape.
- 3.2 Improve retention of Black/African American employees in EII organizations by supporting employee safety and well-being.

Substantial research shows that, for Black/African American families in particular, racially concordant care and representation among service providers are particularly important for positive health outcomes. While data on workforce demographics are not presently available, work group members and listening session participants reported that they rarely encountered staff who shared their experiences as Black/African American families, adding that greater representation would strengthen access, trust, and comfort navigating EII systems. The following recommendations seek to address issues of representation in the EII workforce, while also touching on larger systemic barriers to EII hiring and retention in general.

3.1 Strengthen recruitment of Black/African American employees across the EII services landscape.

To address the lack of Black/African American employees in early intervention systems, the work group recommended conducting more intentional outreach and recruitment:

- Strengthen outreach, including groups such as Black/African American Greek organizations, unions, individuals considering a career change, colleges and pre-med students
- Develop and use recruitment language, imagery and job requirements that demonstrate inclusivity for Black/African American folks, for example:
 - Including lived experience and/or knowledge of African diaspora history, cultural dynamics, vernacular and language as desirable skills
 - Recognizing that language requirements (e.g., bilingual in Spanish) may deter many Black/African American applicants
 - Including statements acknowledging stolen land and labor (example: Labor Acknowledgement- Solid Ground)
- Engage community members/partners with lived experience to ensure appropriateness and cultural relevance of recruitment materials and approaches
- Design hiring processes that promote equity and inclusion, e.g., by ensuring interview/review panels include representation by communities and/or individuals with lived experience
- **Amplify best practices** for hiring of Black/African American staff, such as the <u>Best Practices Hiring Guide for Increasing African American Home Visiting Staff</u>

3.2 Improve <u>retention</u> of Black/African American employees in EII organizations by supporting employee safety and well-being.

Work group members also emphasized the importance of strengthening retention of Black/African American employees in the early intervention workforce by cultivating an environment of safety and healing, livable working conditions and opportunities for growth. Specific strategies include:

- **Strengthen human resources (HR) capacity and readiness** to support employee safety and healing when harm is done, as described in Strategy 2.2
- Cultivate healing practices, services and spaces, as described in Strategy 2.3
- Reduce/eliminate tokenization of Black/African American employees
 - Provide trainings for non-Black/African American employees on how to be allies
 - Accountability Measures that include practices and learning opportunities for non-Black/African American employees that take the burden off of Black/African American employees to teach others
- Offer promotion and growth opportunities:
 - Support employees to grow in their roles and access promotion opportunities

- Consider changing promotion criteria to be more inclusive (e.g., including lived experience as a factor)
- Offer competitive/attractive benefits, and particularly more and/or more flexible time off, creating conditions for rest that make it possible to promote well-being and reduce burnout
- Offer flexible work arrangements when the nature of the work allows, such as
 hybrid work models and allowing employees to remain off camera while working from
 home
- Offer peer mentorship for Black/African American employees to help build a network of support

Emerging Considerations: Self-Determination as a Tool to Promote Equity

DDS's <u>Self-Determination Program (SDP)</u> is a regional center service delivery program designed to provide "individuals and their families with more freedom, control, and responsibility in choosing services and supports to help them meet objectives in their Individual Program Plan"¹ (for example, by working with a provider outside of the regional center's vendor pool). To participate in the program, families must enroll and undergo training about the program, in preparation for playing a more active role in coordinating and documenting services.

Equity Work Group members identified that SDP has the potential to serve as a powerful tool to advance equity by allowing greater parent/caregiver choice in the services their child receives. Yet they noted that the program remains underused despite first being piloted over 10 years ago in 2013. To learn more about SDP and its potential impacts on families of children from birth to age 5, First 5 LA asked the seven L.A.-based regional centers about current SDP usage among young children and its potential for promoting equity going forward. Key learnings are shared below.

Key Learnings about the Self-Determination Program for Young Children:

- <u>Early Start clients (ages birth to 3) are rarely eligible for SDP</u> as the program requires a formal diagnosis, which often comes closer to or after the child's third birthday, when they transition out of Early Start.
- For Early Start families that do qualify, regional centers reported that SDP is rarely, if ever, used, citing a variety of reasons, from parents feeling overwhelmed or just learning the system to having less need for SDP due to the lower caseloads and broader range of available services, compared to those available in Lanterman services (for ages 3 and over).
- Among children ages 3 to 5, some regional centers acknowledged a growing interest in <u>SDP</u> among families, though enrollment remains relatively low. Examples of services sought through SDP by families of young children included social recreation and other community-based opportunities (e.g., dance classes, art lessons, dance, swimming, theater, equestrian, gymnastics).

A majority of regional centers agreed with SDP's potential to promote equity, noting
that informing caregivers about SDP early on can ensure they have access to this tool
even if it does not typically become applicable until children are older. However, some
cautioned that not all families understand or are ready for the additional
administrative burdens that come with enrolling in SDP.

Collectively, learnings from the work group and regional centers suggest that, although SDP has limited applicability for the youngest children, informing parents/caregivers about the program early on can help ensure that they are set up for success and aware of this option as their children reach ages where SDP is more relevant. This can promote equity by supporting parent choice (and eventually child/client choice) as their child ages.

Conclusion

In 2021, we identified critical health disparities in early identification and intervention (EII) that revealed Black/African American families were disproportionately impacted across multiple factors, including service utilization and the cumulative stress of racial inequity, known as weathering (Obeng Gyasi, 2023). Upon reviewing the HMG LA framework, significant gaps emerged: there was insufficient data and no clear strategy designed to effectively engage and support Black/African American families within EII systems. Therefore, we embarked on a journey of intentionality — listening to, engaging with and collaborating alongside Black/African American community members to co-design the recommendations detailed in this report. We sought to identify barriers to EII services and to elevate solutions, provided directly from those with lived experience, to help improve health outcomes for Black/African



American children and their families. The general recommendations can be adapted to different systems and present concrete strategies suitable for funding by philanthropic entities and implementation by health care providers, health plans, hospitals or grassroots organizations alike.

Recognizing that racial equity requires systemic transformation, this report represents a milestone, not an endpoint. The journey toward equitable early intervention services and positive outcomes for Black/African American children and their families must — and will — continue.

Appendix



Help Me Grow LA Equity Workgroup Listening Sessions Report

Methodology

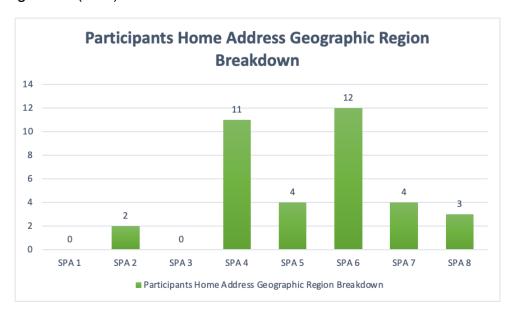
In October 2023, WIN held two listening sessions for Black/African American parents and caregivers of children with or at risk for developmental delays from across Los Angeles County. There was a session held virtually on October 10, 2023, and an in-person session held on October 14, 2023, in Inglewood, California.

Participants and Procedures

Participants were recruited through a variety of outreach strategies including direct outreach at community events, targeted outreach through WIN's existing programs including our Case Management, Community Engagement and Health Equity Team and Family Engagement programs, outreach through partner organizations across Los Angeles County, and through coordination with the Help Me Grow LA Equity Workgroup. Parents and caregivers participated in 90-minute discussions to discuss their experience in accessing or attempting to access early intervention services for their child(ren).

Participant Makeup:

- 36 total participants (26 attended virtually and 10 attended in person)
- 27 mothers, 9 fathers
- Participant home address geographic region breakdown (using Los Angeles Service Planning Areas (SPA):





• 23 participants had children currently 5 years of age or younger. All participants' children were between the ages of 0-4 years of age when services were first sought.

Facilitators

Equipped with an interview manual developed to guide the conversation (see the manual in the attachment section), WIN's Home Team Program Manager and Community Engagement Team Health Equity Program Coordinator were present to facilitate the Listening Sessions. WIN's Director of Programs and three Community Engagement Specialists were present to support with coordination and management of the events.

Selected Responses and Key Data

- 1. When and how did you identify a developmental concern for your child? Did someone else point this out to you or did you observe the concerns on your own?
 - i. 100% of participants who responded to this question indicated that they or a family member noticed developmental concerns in their children.
 - ii. More than 50% of participants indicated that their concerns began between the ages of 1-2 years old.
 - iii. The youngest age that was reported to have a developmental concern was 6 months old (due to physical manifestations of such concerns, specifically head size).
- 2. When you think of early intervention services, what comes to mind?
 - i. Services provided to at-risk or as a preventative means to help small children
 - ii. Services to enrich and aid a child's development
 - iii. Help for young children with disabilities
 - iv. Services that teach the basics of skills that children should be developing
 - v. Occupational therapy
 - vi. Intervening before there is an issue
 - vii. In my experience, it was about asking the hard questions over and over until someone gave me an answer so that is what I think of when I hear this term
 - viii. My child's therapist (WIN)
- 3. Have you heard of Help Me Grow?
 - i. 8 participants shared that they had heard of Help Me Grow. One participant shared that they heard of Help Me Grow at a public community event. One participant shared that her niece was enrolled in services through Help Me Grow when she was young.



ii. 5 participants (who had not heard of Help Me Grow) shared that they had not heard of First 5 LA.

Key Findings

Key Finding #1: Access to early intervention services is hindered by a lack of awareness and education in the community regarding these services.

Several participants shared that they did not know what early intervention services were and did not know such services were available to them until concerns about their child's development arose.

"A lot of families don't know about early Head Start programs or the services available to us. I am fortunate to know these things because of my child development background but not because it is shared widely in our community... my journey to getting connected was about asking the hard questions over and over until someone gave me an answer."

"Most people don't know about these services until their child begins to experience issues and they start looking for help. Some type of community education will be important if we want to solve this problem."

"Many people do not know these services exist so having public campaigns to raise awareness for them like we see for healthcare and mental health care would be helpful for parents."

A participant from South Los Angeles expressed that despite their region of Los Angeles being recognized for receiving substantial public funding, they observe a lack of tangible services and support offered within the community.

Participants shared that it is often too difficult to figure out where to start searching for services while also taking care of multiple children, working, and trying to keep their families stable.

"Making information accessible on social media and other places parents frequent would be helpful for education about these services."

"Schools, churches, and organizations like these that parents regularly engage with should be aware of these services and be able to share them with parents."



Key Finding #2: Parents and caregivers feel that the burden is solely on them to research, educate themselves, initiate Regional Center evaluations, and advocate for their children's needs.

Several participants indicated that they have learned about their child's development on their own through personal reflections and observations of their child.

"School doesn't teach you how to navigate through the system or how to have a child with developmental delays."

"I haven't been able to get intentional answers and information about my child's development. Most of us are just learning through experience on the way."

More than half of the participants shared that they learn about child development through internet research and parenting programs - Black Infant Health and the Regional Center were referenced as sources of learning for participants.

"When my son turned 1 year old he was not walking and I was concerned. I made a referral to the Regional Center for him. I could have waited but I didn't want to lose months of services waiting to see if he would start walking. I had to keep following up to get an update. My child care provider was afraid to talk to me about it and so were my parents because they were afraid of how I would respond."

Key Finding #3: Parents and caregivers look to their primary care providers and office staff to educate and support them in learning about and accessing early intervention services, but most do not feel that they are getting what they need from their providers.

100% of families who participated indicated their child's healthcare provider as someone they would prefer to receive information about their child's development and shared that the sooner they recognize concerns in their child the better.

"We need clear direction from our child's health care providers with support, resources, and guidance at visits."

One participant also added that they would appreciate their pediatrician providing them with details on what to expect for the next 6 months after their doctor's visit to help them prepare.

Participants also shared the importance of representation in our care systems.



"We need people in these provider systems that look like us to advocate for us."

"If my provider looks like me I feel like I can communicate more freely because they understand me better."

Key Finding #4: Black and African American families do not feel heard, seen, or respected by their providers because of their race, ethnicity, and social status.

Two families shared similar experiences of taking their children outside of their neighborhoods to receive primary care (specifically Westwood and Beverly Hills hospitals and doctor's offices); however, their experience has been feeling ignored, unseen, and uncomfortable in those spaces. Both expressed that they feel this is connected to race and class because they are still experiencing the same issues in the system despite going to better-quality locations.

Another participant shared that where they live definitely impacts their access to services due to systemic racism and living in a predominantly Black area.

"I work for a substance abuse center and it feels like the staff does not share regional center resources or other related services with our [Black/African American] kids, but they are open to sharing those services with others."

"I went to the doctor to share concerns about my child's development. Another woman of a different race came in after and asked them to take her first because she had to leave. I also had to leave to get back to work but they took her before me anyway. I felt ignored despite being there on time and expressing that need when I arrived."

"We always get a diagnosis but no support. My caucasian coworker has a huge network of support in her child's school including an aide sitting with her son. Our children are labeled as problematic."

"I feel like I have experienced discrimination. My child has yet to be diagnosed. Their teacher pointed out some issues, but instead of the school calling me to try to work with me and sharing information about his behavior they just called DCFS."

"I don't feel like our children are treated as a priority."

"As a Black woman regardless of what the issue is that I express to my provider about myself or my child it feels like I am being dismissed."

"I purposely went to a doctor in Beverly Hills thinking they would give me the best care but I felt ignored. I am not sure if it was because I was a Black woman or because I was in a nice neighborhood or if that was just the doctor's style."



One participant shared that she had their first child in Inglewood and she experienced a lack of communication and clarity from her provider during childbirth. She now exclusively takes her children to Santa Monica to get all of their care and feels like they have the best pediatricians and that her children are finally receiving quality care. This participant also shared that it took her advocating with her insurance company on her own to get her children into a new care system.

When asked what is quality care from providers when concerns about their child's development arise participants shared:

"I just want to feel heard...having someone in the space that looks like me to help me feel more comfortable in finding my voice."

"For me, it means having access to the right services at the right time. This does not happen often, it feels like receiving quality care is a privilege."

"Quality care includes education - my rights, what I am able to ask [my provider] for, and what I am entitled to."

"Treat me like I am human, be sensitive to me."

"Having providers that are educated on how to treat their patients."

Key Finding #5: Opportunities for early intervention and diagnosis are often interrupted by a lack of trust and understanding between families and providers in addition to delays in services and lack of communication between families and the systems serving them.

The majority of participants expressed that they do not trust medical providers due to their own personal experiences of being misunderstood or dismissed as well as family and community experiences in the healthcare system.

"It took me getting a CPS case opened to get my son tested for Down syndrome, my pediatrician looked at him when I asked to test him but she refused because he looked 'fine'."



"Every time I expressed concerns for my son the provider would say "oh he is just a boy...he will catch up". So I didn't feel that my concerns were validated until his issues worsened and it was more than obvious that there was something wrong."

Some participants shared experiences of services being delayed due to a lack of trust and communication from providers.

"I was offered services around development right after I gave birth, but they never came back or shared more information about how to access these services if I needed them."

"My daughter was born a month and a half early so she was developmentally delayed...doctors would keep pushing off the assessments she needed. By the time they finally did the assessments she was older than 2 years old and no longer eligible for some of the services she needed."

"My baby started regressing at 6 months old. My family noticed that his head was getting bigger so I took him to the doctor and asked for a check-up but they wouldn't do any assessments. I took him to another pediatrician and they did it; measured his head, and gave him a referral to CHLA for an MRI. He eventually had to have brain surgery. My doctors were not supportive but I work for a pre-school so thankfully I knew to go to the Regional Center."

Key Finding #6: Parents/caregivers find value in building community with other parents/caregivers to share experiences and support one another through the process of accessing early intervention resources.

A participant from the in-person session shared that having open spaces with other parents like this would be extremely helpful so that she can get answers and support at the moment.

Additional recommendations included mommy cohort groups so that they can build connections and share experiences along the way of their children's development and affinity groups to have intentional spaces for people they can relate to.

Participants suggested support groups that are focused on developmental milestones and early intervention services available to them.

Conclusions and Future Planning



In order to ensure that the expertise and experiences shared by the community are taken into consideration to inform the First 5 LA strategic plan reset and the development of a Help Me Grow LA equity strategy, WIN will share this report along with a live presentation of findings with Help Me Grow's LA Equity Workgroup in November 2023. WIN will also participate in HMG LA equity strategy discussions as needed and provide additional support and guidance based on findings from the community listening sessions. Regardless of the service area, parents and caregivers who participated received resources for early intervention services, case management services, and concrete support. WIN will continue to offer services and linkages to families reached through this process as needed.