

Underrepresentation of Black Infants and Toddlers in Early Start: A Policy Brief

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Background

The Early Intervention Program for infants and toddlers with disabilities was enacted in 1986 under the Individuals with Disabilities Education Act, or IDEA.¹ California's early intervention program, Early Start, is federally funded through Part C of the IDEA and provides coordinated, family-focused evaluation and services for children from birth to age three years meeting eligibility criteria. Currently, children eligible for the Early Start program are those with a developmental delay in areas such as cognition, communication, adaptive functioning, or motor development or those considered to be at high risk of a developmental disability.² In California, early intervention services are primarily coordinated and delivered through its 21 Regional Centers.

Data from the 2001 Early Childhood Longitudinal Study Birth Cohort found that nearly 13% of children between 9 to 24 months had developmental delays making them eligible for early intervention, yet only about 10% received services.¹³ In this cohort, Black children were less likely to receive services compared to children of other races or ethnicities.¹³ Although the overall number of infants and toddlers receiving early intervention services in California has increased in the past 10 years, studies suggest that a projected 3,025 young Californians are still failing to receive needed services.¹⁴

Scope of Problem: Access Disparities for Black Children

Studies have shown that compared to white children with developmental delays, the odds of having delays identified and receiving early intervention services is only 44% for black children.^{3,4} The U.S. Department of Education has reported that the proportion of Black infants and toddlers receiving early intervention services decreased from 18% in 1998, to 13% in 2007, suggesting increasing disparities in access to Early Start services for black children.³ There are multiple factors that may contribute to black children being more susceptible to developmental delays and facing more barriers to accessing early intervention services.

Premature babies are at higher risk of death and morbidity such as vision or hearing problems, cerebral palsy and developmental delay.⁵ In 2018, the rate of preterm birth among black women (14.4%) was 50% higher than that of white women (9.3%) or Hispanic (10%) women.⁵ Studies also show that black families experience more financial and social instability making it more difficult to use early intervention services when offered.⁵ Black mothers also report fear of blame and stigma which impacts their willingness to discuss their own emotional health concerns with their pediatrician. In a study by Magnusson et al., Black mothers reported that they did not have meaningful conversations about

developmental concerns with their child's pediatrician.⁴ Clinicians are also less likely to identify delays in black children and are less likely to offer referral to early intervention without a diagnosed medical condition, which leaves children with mild delays or at-risk conditions without services.³

Previous Interventions

There have been efforts to address this disparity in service utilization amongst black children. Assembly Bill X2 1 (Chapter 3, Statutes of 2016) established the Disparity Funds Program which awarded \$11 million annually to Regional Centers and community-based organizations to implement strategies to increase equity in services.⁸ Projects for the fiscal year 2019/20 include an intergenerational approach to increase awareness and utilization of Regional Center services among black individuals through social media and college outreach programs.⁹ Another project involves holding conferences at local churches to increase awareness of the importance of early detection and intervention for black children with autism to decrease perceived barriers to utilizing Regional Center services.¹⁰

Policy Recommendation

To better address the disparities in receipt of Early Start intervention services for black infants and toddlers, we propose that more funding annually be allocated to conducting outreach to black families providing education about the importance of developmental screenings, recognizing milestones, and improving communication with clinicians. This should be done through provision of additional funds to community organizations such as the Black Infant Health Program (BIH), which is a program that provides resources and education to black pregnant women and mothers. Additionally, more funding could allow for a partnership with existing programs that provide home visits to inform and educate families.

Benefits/Costs

The benefit of providing more funding for outreach programs is that families will be more educated on the importance of seeking out resources and advocating for appropriate developmental services for their child. This will lead to better health outcomes and will reduce overall healthcare costs for maternal and child health services throughout the course of pregnancy and motherhood. Effective provision and referral to Early Intervention services has long been considered an evidence-based policy, with estimated benefit–cost ratios typically in the range of \$2 to \$4 for every dollar invested, when viewed from the societal perspective.¹¹

Partners

The stakeholders related to this policy issue include community organizations led by and in service of black women (including the Black Infant Health program), medical practitioners, black parents and caregivers and insurance providers. Early referral to services can provide essential support to mothers and infants and minimize potential barriers later in life.

Conclusion

Many factors contribute to the underrepresentation of Black infants and toddlers in the Early Start program. Focusing on the stakeholders within this policy allows for increased awareness, outreach and educational knowledge for an at-risk population. We recommend additional funding be allocated annually for outreach to Black families through partnership with community organizations in order to provide education on the services available for children with developmental disabilities. Increasing funding for outreach efforts in order to support black mothers and infants is one important way to decrease the disparities among this population with regard to accessing Early Start interventions.

References:

1. GovInfo. United States Code 2006 Edition Supplement 5, Title 20 Education. <https://www.govinfo.gov/app/details/USCODE-2011-title20/USCODE-2011-title20-chap33-subchapIII-sec1431>. Published 2011. Accessed November 14, 2020.
2. Department of Developmental Services. What is Early Start? <https://www.dds.ca.gov/services/early-start/what-is-early-start/>. Published February 2020. Accessed November 13, 2020.
3. Feinberg E, Silverstein M, Donahue S, and Bliss R. The Impact of Race on Participation in Part C Early Intervention Services. *J Dev Behav Pediatr*. 2011 May; 32(4): 284-291.
4. Magnusson D, Palta M, McManus B, Benedict RE, Durkin MS. Capturing unmet therapy need among young children with developmental delay using national survey data. *Acad Pediatr*. 2016;16(2):145–153
5. Magnusson DM, Minkovitz CS, Kuhlthau KA, et al. Beliefs Regarding Development and Early Intervention Among Low-Income African American and Hispanic Mothers. *Pediatrics*. 2017;140(5):e20172059
6. Evaluating California’s System for Serving Infants and Toddlers with Special Needs. <https://lao.ca.gov/reports/2018/3728/serving-toddlers-with-special-needs-010418.pdf>. Published January 4, 2018. Accessed November 13, 2020.
7. Preterm Birth. Centers for Disease Control and Prevention. <https://www.cdc.gov/reproductivehealth/maternalinfanthealth/index.html>. Published October 30, 2020. Accessed November 14, 2020.
8. California Legislative Information AB-107 Developmental Services Assembly Bill No. 107 Chapter 18. https://leginfo.legislature.ca.gov/faces/billTextClient.xhtml?bill_id=201720180AB107. Published June 27, 2017. Accessed November 13, 2020.
9. Department of Developmental Services FY 2019/20 Disparity Funds Program Project Information. <https://www.dds.ca.gov/wp-content/uploads/2020/06/19-C17.pdf>. Published September 20, 2019. Accessed November 14, 2020.
10. Department of Developmental Services FY 2018/19 Disparity Funds Program Project Information Allie’s Allies. <https://www.dds.ca.gov/wp-content/uploads/2019/09/18-R-SGPRC1.pdf>. Published October 11, 2018. Accessed November 14, 2020.

11. Cannon, J. S., Kilburn, M. R., Karoly, L. A., Mattox, T., Muchow, A. N., & Buenaventura, M. Investing Early: Taking Stock of Outcomes and Economic Returns from Early Childhood Programs. *Rand health quarterly* 2018; 7(4): 6.

12. California Black Infant Health Program.

<https://www.cdph.ca.gov/Programs/CFH/DMCAH/CDPH%20Document%20Library/Communications/Profile-BIH.pdf> Published October 2020. Accessed November 15, 2020.

13. Rosenberg, S. A., Zhang, D., & Robinson, C. C. Prevalence of developmental delays and participation in early intervention services for young children. *Pediatrics* 2008, 121(6), 1503–1509.

14. U.S. Department of Education, Office of Special Education and Rehabilitative Services. 40th annual report to Congress on the implementation of the Individuals with Disabilities Education Act, 2018. www2.ed.gov/about/reports/annual/osep/2018/parts-b-c/40th-arc-for-idea.pdf