United States Senate
WASHINGTON, DC 20510-3205

May 18, 2021

Gene L. Dodaro, Comptroller General of the United States
Government Accountability Office
441 G Street, Northwest
Washington, DC 20548

Dear Comptroller General Dodaro:

We write to ask that the Government Accountability Office (GAO) examine the barriers to States in effectively carrying out Part C requirements under the Individuals with Disabilities Education Act (IDEA), as well as inequities in access to such services for families. Nearly 388,694 infants and toddlers, from birth through age 2, are served under Part C of the Individuals with Disabilities Education Act (IDEA). [1] In fiscal year 2021, Congress appropriated over $481 million in federal funds authorized under Part C of IDEA to help defray the costs of providing early intervention services to infants and toddlers with disabilities.

The first few years of a child's life are critical to their development, which is the primary reason Part C of the IDEA is needed. Part C's intent is to enhance the capacity of State and local agencies and service providers to identify, locate, evaluate, and meet the needs of all infants and toddlers with a disability, beginning at birth (Sec.612(a)(3)). This applies to all children, including highly mobile children, migrant children, children experiencing homelessness, and children in foster care (20 U.S.C. 1412(a)(3)).[2] The law does not set forth a maximum number or percentage of children States must identify during child find services or provide services and supports under IDEA's FAPE requirements. The IDEA sets forth a requirement for States to develop and implement "a statewide, comprehensive, coordinated, multidisciplinary, interagency system that provides early intervention services for infants and toddlers with disabilities and their families." States are to use IDEA funds to coordinate existing early intervention services into an accessible system through state interagency agreements, contracts, and cooperative arrangements designating Lead Agencies in each State to lead and monitor implementation of Part C of IDEA. Although all infants and toddlers with suspected disabilities have the right to early intervention services, the GAO's previous work has documented disparities and barriers to services, including state variance in eligibility for services and assessment protocols, referral sources, and challenges in reaching infants and toddlers of immigrant or dual language learner families or families that

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[1] https://www2.ed.gov/about/reports/annual/osep/2019/parts-b-c/key-findings.html

[2] 20 U.S.C. § 1431(a)(5), P.L. 10-446 § 631(a)(5); 20 U.S.C. § 1400(d)(1); Under Part C of IDEA states also have the option of providing services to children at risk of developing a delay and to children between the ages of 3 and 5. 20 U.S.C. §§ 1431, 1432

live in rural areas.[3] Under Part C, states have discretion in determining eligibility for early learning programs by developing a definition of "developmental delay" and specifying the evaluation and assessment procedures to measure an infant or toddler (20 U.S.C. § 1435(a)(1)). States may – but are not required to – provide services to those infants and toddlers who are at-risk for experiencing substantial delays if they do not receive early intervention services.[4] As a result, a child eligible for IDEA services in one state might be ineligible in another. We are particularly concerned by GAO's previous findings, which indicate states are tightening eligibility criteria by narrowing the definition of "developmental delay" to reduce the number of children eligible for early intervention services and the amount of state fiscal resources spent on these services. Additionally, some children who are likely to be eligible for early intervention services may not be identified or evaluated for needed services based on their access to referral sources. GAO has already reported that various Lead Agencies have unique relationships with referral sources, which can affect the likelihood that the sources will make referrals to a given program. Primary referral sources can include hospitals, physicians, parents, child care and early learning programs, local educational agencies and schools, public health facilities, public health agencies or social service agencies, clinics and health care providers, public agencies and staff in the child welfare system, homeless family shelters and domestic violence shelters and agencies (34 C.F.R. § 303.303(c)). We would like to know the extent to which referral sources are a barrier for families of infants and toddlers with a disability. We believe it is particularly important to understand the extent to which this creates inequities for communities of color, families in rural areas, and immigrant or dual language learner families, in being identified and referred for services.

Furthermore, while Part C of the IDEA requires child find services, evaluations and assessments, the development and review of the IFSP, and service coordination to be provided at no cost to families, parents may be charged a sliding-scale fee for some services. The disparity in fees for certain services poses additional inequities for families in accessing services and could relate to structural racism and bias based on socioeconomic status. A study released in August 2020 by the American Academy of Pediatrics found Black children were diagnosed with autism more than three years after parents expressed concern with their development.[5] We are concerned by those delays and by the continued disparities in screening rates for children of color, in particular between Black, Latino, and Native children and white children of the same age.

Another barrier arises when a child transitions from Part C to Part B Services at age 3, which can result in service disruptions for a child that can be detrimental to their development. GAO has previously reported that the transition from Part C to Part B services results in an array of issues for families and children with disabilities from eligibility criteria and changes in disability definition to coordination of data from a Lead Agency to a State Educational Agency (SEA). Lead Agencies in states vary, and include state health departments, state educational departments (SEAs), or other public agencies, including combined health and human services departments. It

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[3] https://www.gao.gov/products/GAO-19-348

[4] 20 U.S.C §1435(a)(1), P.L. 108-446§635(a)(1). Information on states' definitions of developmental delay can be found at Early Childhood Technical Assistance Center (2016). States' Part C Rules, Regulations and Policies, http://www.ectacenter.org/partc/statepolicies.asp

[5] https://www.aappublications.org/news/2020/08/25/autismdiagnosisdelay082520
https://pediatrics.aappublications.org/content/146/3/e20193629

is critical that Lead Agencies and SEAs coordinate during this time of transition of services for a child.

In light of these concerns, we request GAO's assistance in answering the following questions, and, based on your findings, providing recommendations for future congressional action:

1. What are the key eligibility criteria in States' IDEA Part C programs?
    a. How may States' referral processes contribute to under-identification or under-referrals for services for families from underserved communities?

2. What are the demographics of children receiving services under IDEA Part C, and how do they compare to those of children receiving services under IDEA Part B?

3. To what extent are there differences between States in Part C early intervention program administration, funding, and provision of services?
    a. What are the State trends in fee for service?

4. How do the Lead Agencies help support and monitor local agencies, providers, and LEAs' efforts to implement IDEA Part C and in the transition to Part B services?

5. How does the Department of Education help support and monitor Lead Agencies' efforts to implement IDEA Part C?
    a. How do the offices within the U.S. Department of Education and related agencies engage together in oversight of services provided to infants and toddlers with disabilities, share and communicate data and complaints from the public, monitor family feedback and satisfaction, and issue resources and guidance to States?

Sincerely,

Tim Kaine
United States Senator

Patty Murray

Patty Murray
United States Senator