

Data Brief

Advocates for Children of New York

Protecting every child's right to learn

JANUARY 2021

DELAYED INTERVENTIONS

Early Indicators of the Pandemic's Impact on Infants and Toddlers

In the first few years of life, children's brains are developing rapidly, setting the stage for all future learning. As such, when a child has a developmental delay or disability, these early years provide a critical window of opportunity to intervene and help ensure children reach their full potential. While the full consequences of a global pandemic coinciding with this period in a child's life remain unknown, there have already been alarming repercussions for the youngest New Yorkers: data from the New York City Department of Health and Mental Hygiene (DOHMH) show a striking drop-off last spring in the number of infants and toddlers referred to the Early Intervention (EI) program and evaluated for services due to concerns about possible developmental delays or disabilities. For children who were already enrolled in El when the pandemic hit, their face-to-face services immediately ended. Although the State and City quickly authorized teletherapy, a notable proportion of young children nevertheless saw their services interrupted, putting their progress in jeopardy. While the number of children referred and evaluated for El began to recover as lockdown restrictions were lifted, the data suggest that between 3,000 and 6,000 NYC infants and toddlers—who, absent the

There was a significant decline in the number of children participating in the Early Intervention (EI) program in New York City in 2020, coinciding with the height of the COVID-19 pandemic.

- » During the 4-week period beginning March 22, an average of 135 children were referred to El each week, an 82% decline from earlier in the year, when there were an average 748 referrals per week.
- Due to COVID-19, an estimated 3,000-6,000 young children in New York City were never identified as potentially having a developmental delay or disability.
- » From mid-April through mid-May, there were an average 184 El evaluations per week, compared to an average 558 per week in late January and early February, representing a decrease of 67%.
- » The total number of infants and toddlers receiving El services between July and September 2020 was 15% lower than the same time period in 2019—a difference of nearly 2,900 children.

pandemic, would have been flagged as potentially needing extra support to ensure their healthy development—have fallen off the radar at a time in their lives when every passing week can make a tremendous difference. In fact, during the first quarter of fiscal year 2021 (July-September 2020), the total number of children in the City receiving El services was 15% lower than the corresponding months of 2019, a difference of nearly 2,900 children.

While this analysis focuses on data from New York City, statewide data show similar trends. Across the State, 6,000 fewer children had El service plans in the third quarter of 2020 (July-September 2020) compared with the same period in 2019, a 12% decline. Furthermore, there was a more than 30% reduction in El services billed statewide during the second and third quarters of 2020 compared with the same time period in 2019, suggesting that, in addition to a decline in the number of children identified as needing El services, a significant number of children who already had El service plans did not receive their legally mandated services during the pandemic.

New York must take action to ensure that no child's developmental trajectory is thrown permanently off course as a result of COVID-19. As described in more detail below, the State and City should:

- » Launch an outreach campaign and develop a comprehensive plan for developmental screenings to identify young children with developmental delays and disabilities and connect them to services.
- » Provide technology so that young children do not miss out on evaluations or services due to their families' inability to afford needed devices or internet access.
- Engage in targeted outreach to families to identify and address barriers to participation in services during the pandemic.
- » Provide make-up services to compensate children for the services they missed during the pandemic.
- » Prepare for a potential surge in children needing El and preschool special education evaluations and services.
- » Provide training to El providers to strengthen the quality of remote evaluations and services.
- » Focus discussions about the future use of teletherapy on equity.
- » Report additional data on El referrals, evaluations, and services, including data on racial disparities in service delivery.
- » Increase funding for EI and preschool special education to help address longstanding shortages, cover added costs providers have incurred due to the pandemic, and ensure capacity as the number of children identified as needing services increases.

BACKGROUND

The earlier in life a developmental delay or disability is identified, the sooner a child can begin receiving services, and research suggests that the sooner services begin and the more services a child receives, the greater the positive impact.³ And when children do *not* receive the help they need at the first sign of trouble, they typically require more intensive—and expensive—special education services later on. Given the importance of intervening as early as possible, federal special

education law gives children ages zero to three with developmental delays or disabilities and their families the right to receive evaluations and services, free of charge, to support their cognitive, physical, and social-emotional development. These evaluations and services are provided via the Early Intervention (EI) program, which in New York City is administered by the Department of Health and Mental Hygiene (DOHMH). Infants and toddlers can be referred to the program by a parent, child care provider, pediatrician or health care provider, or other social service professional. A variety of professionals are required to refer children for El evaluations, unless the parent objects, if they suspect the child has a developmental delay or disability. Following a referral, the first step in the El process is a multi-disciplinary evaluation to determine eligibility. Once a child is deemed eligible, an El service plan is developed and they should begin receiving in-person individualized services—such as speech, occupational, and physical therapies—in their "natural environment," such as their home or child care program, unless the nature of their disability requires them to receive services at an El agency.

Approximately 33,000 infants and toddlers in New York City receive Early Intervention services each year. However, estimates of the prevalence of developmental delays suggest that many more young children could potentially benefit from EI than actually participate in the program.5 Moreover, although children have a legal right to be evaluated and receive El services in a timely manner, there are widespread racial and socioeconomic disparities in access, both nationally and in New York. Black children, in particular, are less likely than otherwise similar White children to be referred to the El program and to receive services once found eligible.⁶ In New York City, 15% of infants and toddlers referred to El for the first time in fiscal year 2019 were Black, though Black children comprise about 21% of the total zero-to-three population; one in five Black children who was referred never received an evaluation, compared to approximately one in thirteen White children (7.4%) referred to the program.⁷ Even when young children successfully make it through the first stages of the El process, there are frequently delays in service provision. Between 2016 and 2018, 29% of El-eligible children in New York City—and 39% in the Bronx—did not receive their mandated services on time.8

These already-troubling service gaps have been further compounded by the COVID-19 pandemic and its attendant disruptions to young children's lives. Time is of the essence when it comes to identifying and addressing developmental delays, but, due to the coronavirus, most infants and toddlers spent the spring isolated at home, rather than in the settings where concerns are often first flagged. The closure of most child care programs, for example, meant providers were no longer seeing individual children on a routine basis and were thus unaware of their progress—or lack thereof—with respect to developmental milestones. More significantly, the number of childhood vaccinations administered in New York City dropped considerably during March and April, a sign that parents were postponing routine visits to the pediatrician due to concerns about exposure to COVID-19 or because they were overwhelmed with other responsibilities. Along with delayed vaccinations, a significant consequence of missed pediatric well-child visits is the missed opportunity to screen for developmental delays and disabilities. Nationally representative survey data suggest that the drop in well-child visits was particularly pronounced among low-income Black and Latinx families: 30% of children ages zero to five living in households with an annual income at 150% of the federal poverty level or below missed at least one well-child visit between April 6 and May 18, compared to 23% of children from middle- or upper-income families, while 33% of Black households and 35% of Latinx households with young children reported missing a well-child visit, compared to 27% of White families. 10 Finally, many parents may simply have been reluctant to refer

their young children to a new program in the midst of a public health crisis; those who were facing job loss, coping with illness or the death of a loved one, or working from home while caring for a toddler and supervising older children's remote learning likely had other concerns demanding their immediate attention.

FINDINGS

Data shared by DOHMH at meetings of the Local Early Intervention Coordinating Council (LEICC) in June and October 2020 show that in mid-March, there was a significant drop-off in the number of infants and toddlers referred to the Early Intervention program in New York City due to concern about a possible developmental delay or disability. 11 Although El was considered an "essential service" and continued operating throughout the pandemic, Citywide referral counts fell precipitously the week of March 15—coinciding with the closure of the City's public schools—and dropped even further the following week, when Governor Cuomo's executive order closing all nonessential businesses went into effect. Referrals remained extremely low through the worst weeks of the pandemic; an average 135 children were referred each week for four consecutive weeks, beginning with the week of March 22, representing an 82% decline from the four-week period beginning January 19, when there were an average 748 referrals per week (see Figure 1).

The plummet in referrals was followed shortly thereafter by a similar—though slightly less dramatic—decline in the number of completed multi-disciplinary evaluations to determine children's eligibility for services. New York State authorized remote evaluations for El on March 19th, and in New York City, providers transitioned to remote evaluations relatively quickly. Even so, there were only an average 184 evaluations per week from mid-April through mid-May, compared to an average 558 per week in late January and early February, representing a decrease of 67% (see Figure 2). As the decline in evaluations reached its nadir about a month after the lowest point for referrals, this drop-off was likely attributable to the fact that there were fewer children in the pipeline to evaluate in the first place.

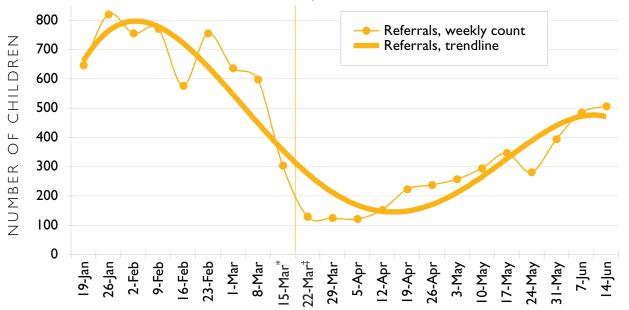
In late April, the number of children referred to Early Intervention each week began slowly and steadily increasing. With the exception of the week of Memorial Day, when referrals again dropped, each week saw a greater number of referrals than the week before. Evaluations began recovering shortly thereafter; the number completed trended upward—excluding a dip around Memorial Day from mid-May onward. However, as of the beginning of the summer, Citywide referral and evaluation counts both still remained significantly below pre-pandemic levels. During the first three weeks of June (i.e., the three-week period beginning May 31), there were an average 463 referrals per week, 38% lower than the weekly average for January 19-February 9. Similarly, there were an average 253 evaluations per week in early-to-mid June, 55% below average weekly counts early in the year.

While there was variation in the number of referrals and evaluations from week to week in winter and spring 2019, it was not nearly as extreme as that seen in 2020. During the corresponding time period in 2019, Citywide referral counts generally hovered in the range of 650-750 children per week; at no point from mid-lanuary through mid-lune 2019 did weekly referrals drop below 500 children. Assuming that, absent the pandemic, 2020 would have been similar to preceding years, this suggests that there are between 3,000 and 6,000 young children in New York City who were never referred to the Early Intervention program as a consequence of COVID-19.

FIGURE I

There was a significant drop in the number of children referred to EI in spring 2020, coinciding with the height of the COVID-19 pandemic in New York City.

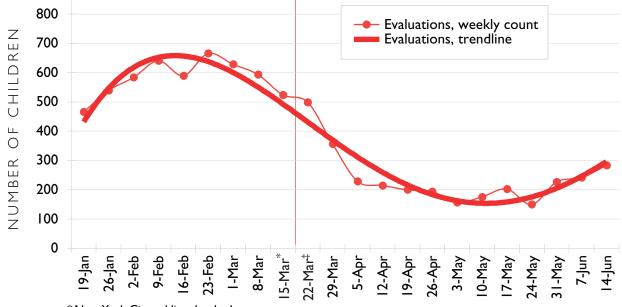
As some random fluctuation from week to week is to be expected, the thick line shows the overall trend in referral counts.



^{*} New York City public schools close

FIGURE 2

The drop in referrals was followed by a decline in the number of children evaluated to determine their eligibility for EI services.



^{*}New York City public schools close

SOURCE: DOHMH presentation at the June 26, 2020 meeting of the Local Early Intervention Coordinating Council (LEICC).

[‡] New York State PAUSE goes into effect

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Though weekly referral and evaluation counts are not publicly available beyond mid-June, the overall positive trend that began in late spring continued over the course of the summer, with referrals and evaluations beginning to approach pre-pandemic levels by late September. 12 However, the total number of new and re-referrals between July and September 2020 still remained 13% lower than the same three-month period in 2019 (7,530 in 2020, compared to 8,664 in 2019). In addition, fewer children in New York City received Early Intervention services this past summer than the prior year: a total 16,018 infants and toddlers received services between July and September 2020, compared to 18,911 children in 2019—a difference of nearly 2,900 children and a decline of 15%. Even those children who count as receiving El services in summer 2020 were receiving some but not necessarily all of the services to which they were entitled.

In addition to children who never started the El process as a result of the pandemic, many young children with developmental delays and disabilities who were already receiving services stopped getting them when the City shut down in March. Though many providers transitioned to teletherapy relatively quickly, according to phone surveys conducted by DOHMH between April and mid-June, nearly one in four families (24%) were not receiving any of their Early Intervention services as of the time they were surveyed. 13 Of those, 7% were experiencing problems related to technology or internet access and 14% were having issues with their service provider; in the remaining 79% of cases, DOHMH indicated it was the "family's choice" to forego services because of limited time capacity, the perception that services provided remotely were not benefitting their child, or some other reason.

Although categorized as the "family's choice," Advocates for Children's conversations with families over the course of the pandemic suggest that many families did not have a workable option for their child to receive effective services. With limited child care available and the need for an adult to be fully present to help the young child for the duration of each remote El session, teletherapy proved logistically impossible for many working parents. Other families attempted to use remote services but ended them because their children were not benefitting. Some families also reported to DOHMH that service coordinators or therapists discouraged them from pursuing teletherapy as an option.

For other parents, the decision to forego services may have been heavily influenced by a lack of adequate technology. Approximately 15% of City households have no access to the internet, 14 and although the Department of Education (DOE) provided iPads with free data plans to preschool and school-aged students to enable them to participate in remote learning, the City did not provide any such devices to families of children receiving El services. Some families who lacked a laptop or tablet and attempted to access teletherapy via a cell phone found that small screen or audio-only services—where the parent and child could not see the therapist and the therapist could not see the child or the parent—were ineffective for their infants and toddlers. While the State and City now allow El services to be provided in person, they are encouraging the continuation of remote services, so concerns about access to teletherapy persist. Finally, while 76% of families were receiving at least some of their El services at the time they spoke to DOHMH, they were not necessarily receiving all of the services that they had previously been identified as needing.

RECOMMENDATIONS

Given the significant decline in the number of children referred to the Early Intervention program and evaluated for services, as well as the number of infants and toddlers who did not receive their mandated El services during the pandemic, New York State and City must take immediate action to ensure that young children with developmental delays and disabilities get the services they need as soon as possible at the time in their lives when intervention has the greatest impact. We recommend the following steps:

Launch an outreach campaign and develop a comprehensive plan for developmental screenings to identify young children with developmental delays and disabilities and connect them to services.

Under federal law, the State and City have an obligation to identify infants and toddlers who have developmental delays or disabilities and need El services. Given the impact of the pandemic, the State and City must increase outreach to identify these children.

Since children and families are still not interacting as frequently with doctors, child care providers, and other professionals who are responsible for identifying a child's potential need for developmental services and informing families about EI, the program should find new ways of reaching families. For example, El should engage in a community outreach campaign, such as a statewide El Awareness month, aimed at educating families on developmental milestones for children under three and how families can get help through El if children are not meeting those milestones. El should explore various media options, including print, television, and radio, in multiple languages in order to reach families in low-income communities of color that have been most impacted by the pandemic and have historically been underserved by the El program. The State and City should also use available data to identify communities with low referral, evaluation, and service rates to conduct targeted and proactive outreach. El should engage stakeholders, including community-based organizations, in these efforts.

At the same time, although certain professionals are having less frequent and shorter interactions with families, EI must emphasize the continued obligations that professionals have to identify children with developmental delays and disabilities and the need to incorporate developmental screenings and information about the EI program into their discussions with families during doctors' visits, at child care and early childhood education programs, in shelters, and in other settings. We are pleased that New York City has efforts already underway to have Health and Hospitals (H+H) incorporate discussions about child development into doctors' visits, facilitate the referral process for pediatricians, and increase the communication between the El program and hospital staff in order to better support families throughout the referral and evaluation process. Given the decline in referrals, El should expedite and expand such efforts to other settings.

In addition, the State and City should develop and fund a comprehensive plan for developmental screenings to ensure every young child is screened and that children with developmental delays and disabilities are identified and referred for services as early as possible.

Provide access to technology.

The State and City should ensure that families have access to internet-enabled devices necessary for remote evaluations and services. Currently, the City is providing iPads with LTE data to preschool and school-aged students so that they can engage in remote learning. However, even though the El program is encouraging families to receive evaluations and services remotely, the City does not have a similar option for families of children participating in El. While El allows children to receive services over the phone, the challenges of providing remote services like physical therapy are compounded when the therapist cannot see the child and parent and the parent and child cannot see the therapist. The need for technology may increase further as COVID-19 positivity rates rise and families who have selected in-person services need to resort to remote services.

The ability to receive El evaluations and services must not be dependent on a family's ability to afford a device and internet service. The State and City should secure devices with online connectivity (for example, laptops and hotspots or devices with cellular data) that they can loan to families who need them in order to participate in Early Intervention.

Identify and address barriers to participation in services.

The State and City should issue guidance directing Early Intervention service coordinators to reach out at least once per month to families whose children are not receiving their mandated services and work to identify and address the barriers preventing their participation. Such outreach should include contacting families who chose to suspend or terminate El services during the pandemic to ask if they want to resume El services and address any challenges they may be facing. For example, families who chose not to receive services remotely due to concerns about the effectiveness of teletherapy should be informed that in-person services are now available for their child; families who are not participating due to lack of technology should receive a device; and parents who are unable to spend hours during the workday assisting remote therapists in providing services to their children should be offered services at a time that works with their schedule. The guidance should also include reminders about the obligation service coordinators have to assist families with the transition to preschool, regardless of whether or not children are currently receiving their mandated El services. We are pleased that the City will be providing professional development for service coordinators in anti-bias and traumainformed services. To help service coordinators work effectively with families, such professional development should be available statewide.

Provide make-up services.

Under federal law, children who have not received their legally required El services have the right to "compensatory services" to make up for the instruction and therapies they lost. The State and City should develop a system for identifying which children with disabilities—including those who aged out of the program during the pandemic—require compensatory services, determining what services they need, and providing those services in a timely and flexible manner. Without such a process, individual families would need to request administrative hearings for make-up services, requiring parents to jump through cumbersome legal hurdles that will favor those who are able to afford lawyers and leave children from low-income families behind.

Prepare for a potential surge in referrals and need for services.

During the pandemic, the State and City experienced a steep decline in the number of El referrals and the services provided to children. As New York works to reopen and as children return to child care centers and preschools, the State and City must prepare for the possibility of an influx in El referrals for children still under three and preschool special education referrals for children three and older. The El and preschool special education programs need to be prepared to process these referrals, conduct evaluations, and provide services within legally mandated timelines, including having the staff needed and seats available in centerbased programs. They must ensure that they have the capacity to work with an increased number of children, including children who may require more significant interventions because they were referred late and spent months without any developmental services. Among other steps, the State Education Department should develop an expedited process for approving new preschool special education classes and allowing existing programs to adjust the staffing ratios of their classes based on the need.

Provide training to El providers on remote services.

Before the pandemic, New York State did not provide any remote El services. We appreciate that providers worked quickly to adapt to new platforms to provide services so that children would not experience a gap. As use of teletherapy continues, it is important to train providers on how to effectively work with children and families through this approach. In doing so, the El program should seek input from families and providers on what kind of training would be most helpful to improve the quality of remote services.

Focus discussions about the future of teletherapy on equity.

As the El program considers authorizing teletherapy as a permanent service delivery option after the pandemic, the State and City must study the efficacy of teletherapy as a model and work to ensure equity in service delivery, so that remote services do not become an inappropriate substitute for in-person services in historically underserved communities. While teletherapy has the potential to reach families who struggle to access in-person services, it is also essential that the El program does not create a two-tiered system in which some communities have the option of in-person and remote services, while others—particularly rural and low-income communities of color—are only offered services remotely. The State and City must develop guidance and standards regarding the recommendation and provision of teletherapy services that take into account the effectiveness of the services, the individual needs of the child, and parent preference, so that teletherapy is not recommended based solely on provider availability. In addition, the State must conduct a thorough analysis of appropriate payment rates for teletherapy and in-person services with a focus on providing high-quality services to all children, including children in underserved communities.

Report State and City data on El referrals, evaluations, and services, including data on racial disparities in provision of El services.

Last year, AFC and Citizens' Committee for Children (CCC) released a report showing the longstanding disparities in access to El services by race and income in New York City. 15 The State should publicly report referral, evaluation, and service data before, during, and after

COVID by race to help identify trends across the State and create a targeted response to address racial disparities and barriers that families face in securing services. While the City has provided some disaggregated data on the weekly number of referrals, evaluations, and IFSP meetings during the pandemic, the City has not publicly reported on the number of children missing their mandated El services disaggregated by race and should do so. In addition, the City should submit the report required by Local Law 21 of 2020 to provide additional data on children receiving El services.

Increase funding for Early Intervention and preschool special education.

Inadequate State funding over many years has led to a shortage of El providers and preschool special education programs, leaving young children with developmental delays and disabilities without the services they need and have the right to receive. In fact, payment rates for El providers are lower than they were in the 1990s.

Despite the decreased numbers of children referred for El and preschool special education programs during the pandemic, we continue to hear from families whose children are not receiving their legally mandated services due to these shortages. The pandemic has only added financial challenges, including the cost of personal protective equipment for in-person services, that have made it even harder for these programs to continue operating. Particularly given the potential need to serve an influx of children who may need more intensive services after going months during the pandemic without receiving needed services, the State must increase the reimbursement rate for EI providers and preschool special education programs by at least ten percent.

Given the importance of increasing these rates, the **State must explore all possible sources of** revenue including the "covered lives" proposal that would require commercial health insurance companies to contribute a set amount to the cost of El services instead of billing them for each individual service claim, the majority of which get rejected.

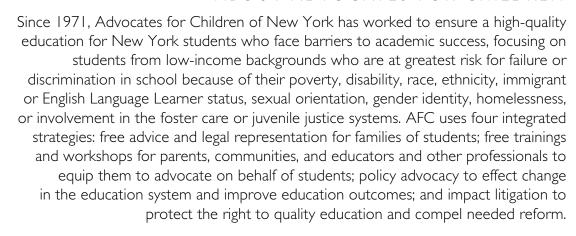
The State should also conduct a cost study, with stakeholder input, for El and preschool special education to assess and recommend changes to the methodology used to determine payment for these services and programs to help address capacity challenges, especially in low-income and underserved communities.

Finally, the State must ensure localities have the funding they need to administer the El program and help implement the recommendations in this report. In June 2020, the State began withholding 20 percent of most payments to localities, including funding for El. Given the importance of El and the needs of the program stemming from the pandemic, the State should immediately provide localities with the El funding withheld and should exempt El from any future withholdings.

NOTES

- ¹ New York State Department of Health, Updated Fiscal Agent Data PowerPoint, December 3, 2020 meeting of the Early Intervention Coordinating Council (EICC), p. 4. Webcast available at: https://totalwebcasting.com/view/?func=VOFF&id=nysdoh&date=2020-12-03&seq=1.
- ² New York State Department of Health, Updated Fiscal Agent Data PowerPoint, p. 6.
- ³ See, e.g., Litt, J.S., Glymour, M.M., Hauser-Cram, P., Hehir, T., & McCormick, M.C. (2018). Early Intervention services improve school-age functional outcome among neonatal intensive care unit graduates. *Academic Pediatrics*, 18(4), 468–474. https://doi.org/10.1016/j.acap.2017.07.011
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- ⁴ NYC Department of Health and Mental Hygiene (DOHMH), presentation at the November 15, 2019 meeting of the Local Early Intervention Coordinating Council (LEICC). Minutes and data report retrieved from: https://www1.nyc.gov/assets/doh/downloads/pdf/earlyint/leicc-min-11152019.pdf
- ⁵ See, e.g., Rosenberg, S.A., Robinson, C.C., Shaw, E.F., & Ellison, M.C. (2013). Part C Early Intervention for infants and toddlers: Percentage eligible versus served. *Pediatrics*, 131(1), 38–46. https://doi.org/10.1542/peds.2012-1662
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- ⁷ NYC DOHMH, presentation at the November 15, 2019 LEICC meeting.
- ⁸ Advocates for Children of New York & Citizens' Committee for Children of New York, *Early Inequities: How Underfunding Early Intervention Leaves Low-Income Children of Color Behind* (December 2019). Retrieved from: https://www.advocatesforchildren.org/sites/default/files/library/early_inequities.pdf
- ⁹ Langdon-Embry, M., Papadouka, V., Cheng, I., Almashhadani, M., Ternier, A., & Zucker, J.R. *Notes from the Field:* Rebound in routine childhood vaccine administration following decline during the COVID-19 pandemic New York City, March 1–June 27, 2020. *MMWR Morbidity and Mortality Weekly Report* (July 31, 2020), 69:999–1001. http://dx.doi.org/10.15585/mmwr.mm6930a3external.icon
- ¹⁰ Rapid Assessment of Pandemic Impact on Development Early Childhood Household Survey Project (RAPID-EC Project) at the University of Oregon, "Health, Interrupted: Well-child visits are declining during the COVID-19 pandemic" (May 26, 2020). Retrieved from: https://medium.com/rapid-ec-project/health-interrupted-a463733ce3c5
- The rate of missed well-child visits did not decrease as the pandemic continued; 32% of low-income families with children ages zero to five reported a missed visit between April 6 and October 6. See: RAPID-EC Project, "Health (Still) Interrupted: Pandemic continues to disrupt young children's healthcare visits" (October 13, 2020). Retrieved from: https://medium.com/rapid-ec-project/health-still-interrupted-pandemic-continues-to-disrupt-young-childrens-healthcare-visits-e252126b76b8
- ¹¹ NYC DOHMH, presentation at the June 26, 2020 LEICC meeting. Minutes and data report retrieved from: https://www1.nyc.gov/assets/doh/downloads/pdf/earlyint/leicc-min-06262020.pdf

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¹² NYC DOHMH, presentation at the October 16, 2020 LEICC meeting. Data report retrieved from: https://www1.nyc.gov/assets/doh/downloads/pdf/earlyint/leicc-min-10162020.pdf

¹³ NYC DOHMH, presentation at the June 26, 2020 LEICC meeting. Webcast available at: https://youtu.be/48x219d2sUY?t=6245

¹⁴ Citizens' Committee for Children of New York, Keeping Track Online: Household Internet Access (2019). Retrieved from: https://data.cccnewyork.org/data/map/1325/household-internet-access#1325/a/3/1547/62/a/a

¹⁵ Advocates for Children of New York & Citizens' Committee for Children of New York, Early Inequities (2019).