Centering the Family Experience

IMPLICATIONS FOR LONG ISLAND'S EARLY CHILDHOOD SYSTEM
Overview

Help Me Grow – Long Island (HMG-LI) is an Island-wide partnership that aims to improve developmental outcomes for young children and their families. As part of its activities, HMG-LI offers a free service via its Centralized Access Point that connects families and providers to community resources and child development information in Nassau and Suffolk counties. HMG-LI provides ongoing support to families by phone, text, and email to meet the needs of their young children, and trains providers like physicians and early childhood educators to use developmental screens with the families they serve.

In HMG-LI’s 2nd annual report, we highlighted the role that HMG-LI Centralized Access Point played in assisting families navigate changing conditions during COVID-19. Much of this information focused on descriptive data highlighting how many families were served, what they needed and how HMG-LI helped them. However, quantitative data alone doesn’t tell the whole story. Therefore, in fall of 2020 we met with some of the families served by HMG-LI to put stories to the numbers and identify themes in families’ experiences.

The interviewed families, who were representative of HMG-LI’s population served, indicated that HMG-LI helped them connect to services while also providing intangible and invaluable support during a difficult time. Their stories demonstrate how HMG-LI provides the extra support and guidance needed in overcoming common barriers to accessing services. This was HMG’s intended purpose when it was launched on Long Island by a network of stakeholders in 2018: ensure that all families access the services available to help them. Yet, while HMG-LI addresses inequities in the early childhood system by helping individual families navigate the process, it is incumbent upon the entire community to make improvements to remove these barriers so the system serves all families.

This report presents the following:

- Help Me Grow – Long Island promoted protective factors among participants, in addition to connection to services. (Section 1)
- Children that would benefit from preschool special education are being lost in the process of seeking services. (Section 2)
- Steps can and should be taken at the state, district, and individual level to ensure that all children and families can access the services available to help them. (Section 3)

1 HMG-LI is overseen by a Leadership Team of 30 member agencies and is administered by Docs for Tots.

2 The Strengthening Families Protective Factors Framework (from the Center for the Study of Social Policy) looks at characteristics of families that mitigate risk and promote optimal development and outcomes. They include parental resilience, social connections, knowledge of parenting and child development, concrete support in times of need, and social emotional competence of children.
In the fall of 2020, HMG-LI embarked on a qualitative interview process with families that had cases representative of the larger population served. In total, 7 families completed interviews. The purpose of this qualitative evaluation was threefold: how does HMG-LI promote family protective factors, what are the primary barriers to early childhood developmental health on Long Island, and how does HMG-LI directly address those barriers?

The main themes expressed during these interviews were as follows:

- Help Me Grow – Long Island enhanced protective factors among participants.
- Families expressed that they found HMG-LI valuable and were satisfied with the level of support we provided to help them meet their needs.
- All families faced obstacles in obtaining services and were assisted by HMG-LI to successfully connect.

The families interviewed are representative of HMG-LI’s families: nearly half were Spanish-speaking and the other half English speaking; most were mothers, but fathers and grandmothers also participated; they spanned both counties; their family composition was varied. Most families had connected with HMG over developmental concerns, but some also asked for help with basic needs, and many were connected to additional caregiver supports, like child care and support groups.

4 See footnote 2 for more information about protective factors.

5 Bright By Text is an evidence-based text messaging service to promote parental resilience and child development. See https://brightbytext.org/
The main themes expressed during these interviews were as follows:

Enhancing Protective Factors
Aside from successful connection to helpful services, families repeatedly expressed that HMG-LI provided emotional support that empowered the families even beyond their experience with HMG. While HMG directly addresses protective factors like accessing basic needs, knowledge of child development, and child’s social emotional competence, these conversations with families highlighted how the model also enhances parental resilience—a parent’s ability to respond to stressful situations—and social supports.

Parental resilience
Strengthening Families defines parental resilience as managing stress and functioning well when faced with challenges, adversity, and trauma. To measure this factor, we asked “How well do you feel you can handle stressful situations that come up with your child? Has this changed since connecting with HMG-LI?” Responses included references to how the HMG Specialists were able to give parents confidence in their ability to work with their children and motivate them to move forward.

“[HMG Specialist] gave me hope to continue with my child. There were things that I had no motivation for but [she] did help me, and thanks to her and Help Me Grow, I did what I could to help my child.”

Social Connections
This is defined as having positive relationships that provide emotional, informational, instrumental, and spiritual support. Participants felt comfortable in their relationship with the HMG Specialists. Parents reported that they felt they could reconnect with HMG as needed, and that their questions would be heard and answered. This in turn allowed them to take the recommended actions.

“Everything actually prospered for me, actually knowing that I had somebody that I can talk to from a distance... Someone that guides me.”

Satisfaction and Value of HMG-LI
All families expressed the value of HMG-LI and satisfaction with the level of support we provided in helping them meet their needs. Participants expressed that they were helped in connecting to services, and that HMG would regularly follow-up with them to make sure.

“I have to say, you guys have been great ... I see how you treat people, or my child in his time of need, to help those needs being filled or resolved. I have to say that I’m impressed.”

Obstacles despite HMG-LI services
All families faced obstacles in obtaining services. The families that utilize HMG-LI are often dealing with a number of family stressors, including struggling with the high cost of living, unstable housing situations, unreliable access to transportation, and lack of time during the day due to work or child care responsibilities. Despite HMG-LI working with these families to successfully connect to programs that could help, they faced many barriers such as:

- Not being able to easily get in touch with service providers
- Having difficulty getting information or receiving services due to language barriers
- COVID-19 affecting the availability of or process for receiving services
- Having difficulty with transportation to obtain services; even when reliable transportation was available, the cost of things like gas money to travel to agencies for assistance was a burden, especially when multiple trips are required
- Facing barriers and delays to requesting preschool special education services** (see box “Preschool Special Education” for more detail)
Equity in LI’s Early Childhood Systems

**Equity** is the just and fair inclusion into a society in which all can participate, prosper, and reach their full potential. As such, achieving equity benefits everyone.

Long Island faces issues in equity, particularly for Hispanic and Black families. Historic racial segregation has led to lasting, unequal opportunities.

Available does not equal accessible. Long Island has a wide range of services that can help improve child outcomes, such as developmental support services. However, it is often the families that need help the most that face the most barriers. These barriers need to be addressed in order to realize benefits for all families.

“Every system is perfectly designed to get the results it gets.” While it is important to address barriers with each individual family, broader, systemic changes are needed to ensure equitable and sustainable access for all families.

Addressing equity on Long Island requires looking at the barriers that primarily affect people of color and from lower socioeconomic households and take steps to remove these barriers.

Many of the interviewed families had been working with HMG to get a preschool special education evaluation through their school district, often facing the most barriers right at the start of the process. They reported that schools on Long Island require parents to register their child before requesting an evaluation, and registration requires extensive documentation that may be difficult to obtain in a timely manner. This made the process very long, and particularly challenging for families that are low-income or are from BIPOC (Black, Indigenous, and People of Color) communities.

As a result:

- Families experienced excess stress and frustration
- Caregivers wanted to quit the process
- Time was wasted during a critical developmental period

The systemic barriers faced by HMG-LI’s families demonstrate how, despite having numerous available services, Long Island can take steps to ensure equitable access to these services. Section 2 outlines how current processes in our school systems can be particularly challenging for families of color and lower socioeconomic status, and Section 3 suggests recommendations to address these inequities.
Preschool Special Education

What is it?

“Preschool special education” is a program for children ages 3-5 who, because of mental, physical or emotional reasons, have been diagnosed with a disability and can receive special services through the child’s school district. Preschool special education services and programs are provided at no cost to the parent.

- These services are commonly preceded by IDEA “Part C” services, or Early Intervention (EI) for eligible children under the age of 3 through the child’s local Early Intervention Program. In New York, EI service coordinators assist with making referrals and transition planning for children who receive EI and who may need to continue with preschool special education services.

If a parent of a child between the ages of 3-5 were concerned about their child’s development and they have not previously received EI services, they must submit a written request to evaluate their child to their school district’s Committee on Preschool Special Education (CPSE) to formally request an evaluation that would deem the child’s eligibility for these services.

The school district must obtain the parent’s consent to evaluate and is legally required to complete an evaluation within 60 days of receipt of such consent.

Preschool Special Education on Long Island

Between Nassau’s 56 school districts and Suffolk’s 69, there are 125 school districts in the Long Island region, far more than in any other NY county or region—including New York City. This translates into 125 different processes for requesting an evaluation for Preschool Special Education, most of which require completing school registration paperwork before being able to formally request an evaluation. Examples of this are delineated in Section 2.
Long Island Preschool Special Education Evaluation Process with HMG-LI Case Findings

**AVERAGE TIME FOR HMG-LI CASES (107 Days Total To Complete Process)**

1. **Family decides to seek services for potential delay in child 3-5yo**
2. **Family receives instructions on how to register child for school**
3. **Family receives school district registration paperwork**
4. **Family completes registration paperwork (see registration requirements below)**
5. **Family submits registration paperwork and has in person or zoom meeting with school district to complete registration (not all school districts require meetings)**
6. **Family requests and consents to evaluation & completes additional evaluation paperwork**
7. **Schedule evaluation**
8. **Receive evaluation**
9. **Have meeting to establish Individualized Education Plan (IEP)**
10. **Start services**

**STEPS AT WHICH HMG-LI FAMILIES DROPPED OUT OF THE PROCESS**

- 23% drop out at this step - never call the district
- 51% drop out in this step - never hand in paperwork
- 17% drop out in this step - never get to evaluation being scheduled
- 9% drop out in this step - evaluation scheduled but never completed

*Children that are found ineligible for services would not proceed to the IEP meeting. However, of the HMG-LI families that made it to evaluation, 100% were found eligible for preschool special education services.*

Analysis for this report focused solely on the process up to evaluation. We do not have data to report regarding the timeliness of the last 2 steps of the process.

*Percentages reflect only the families in our dataset that did not make it through to evaluation.
SECTION 2

Access to Preschool Special Education

Children that would benefit from preschool special education are being lost to the process:

Nearly half of all children aged 3-5 in Help Me Grow – Long Island’s system have developmental concerns for which their families are pursuing assistance. During the year, HMG-LI worked with 72 families with developmental concerns that required a preschool special education evaluation for them to receive services. HMG-LI guides parents through the preschool special education process by talking them through the steps, providing a letter template to request an evaluation, helping get the right school district paperwork for registration, and keeping up with families throughout the process.

- Despite this intensive support, during the current reporting period only 36% of HMG-LI families (n=26) made it all the way through to evaluation. Of those, 100% qualified for services, which is far higher than the average eligibility rate.

- This supports the notion that HMG-LI families are typically more vulnerable and suggests that the families that dropped out of the process before receiving evaluation were likely to have qualified for services had they completed an evaluation.

- Based on the barriers causing the registration delays, this issue may disproportionately affect families of color.*

Our analysis of the available data highlighted that the requirement by many Long Island school districts to register the child before requesting evaluation resulted in:

- 51% of families (n=18) dropping off the process after receiving the extensive registration paperwork

- Delayed evaluation by an average of 2 months for those that proceeded (i.e., doubled the amount of time to complete the entire process)

- Creating barriers that disproportionately affected people of color and families in low-income households

Most of the families that do not complete the process would not be known to the school district, as they drop off before the request for evaluation is received. Although COVID did affect some families that were in process and delayed others from starting pursuit of services, these issues existed pre-pandemic.

<table>
<thead>
<tr>
<th>Time from receipt of school district registration paperwork to actual registration</th>
<th>Time to complete evaluation once requested/consent received</th>
<th>Total length of process</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average # of days</td>
<td>51 days</td>
<td>56 days</td>
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* The demographics of those referred to CPSE during the reporting period reflected that of our general HMG population, with 97% of families identifying as Hispanic, Black, Asian, or “other”

6 Cases were excluded from the analysis if 1. the child was already getting CPSE services but had interruption/issue with services requiring assistance, 2. if CPSE referral was already in progress when connected to HMG, 3. if there is not enough information about when referral/evaluation was done, and 4. if caregiver/parent declined to use the CPSE referral, quit in the process, or was lost to follow-up. The analysis was then completed on a total of 22 cases to calculate time elapsed, with additional analysis completed on the excluded 50 cases to determine reason for drop-off, if applicable.
What’s the problem? That on Long Island, many school districts unnecessarily delay the student registration process, which in turn causes substantial delay of these students’ preschool special education evaluations. The IDEA (Individuals with Disabilities Education Act) requires that school districts evaluate a child within 60 days of receipt of parental consent, and getting services to young children is an effective investment in improved outcomes. School districts in other regions in the state allow parents to request an evaluation while simultaneously starting the registration process, such as in the southern region (12 counties around Binghamton), and New York City. Unfortunately for families on Long Island, the requirement to enroll in the district before submitting an evaluation request adds significant time to the process. As far as we can determine, the requirement to complete registration is not prohibited. Student registration on Long Island, however, can be an arduous process, causing a delay in commencing an evaluation by an average of 51 days in our sample of high-needs families. Examples of requirements for school district registration on Long Island include:

- Providing multiple proofs of residence and/or an affidavit from a landlord or other third party, which can be challenging or even impossible to obtain for those in unconventional housing or with immigration status concerns
- Having a physical and paperwork completed by a physician, which requires a doctor’s visit, which was made more challenging to acquire during the pandemic
- Only having one way to obtain the necessary paperwork (i.e. either by coming in person or by submitting completely online), and not having the paperwork available in other languages
- Making parents come in person for a meeting to complete registration, which can be challenging for those who work or do not have transportation
- Requiring notarization of documents without informing families of the existence of a notary at the school district’s offices to assist them
- Only being applicable to each specific school district—in other words, because each school district has its own paperwork and requirements, a family that moves during the registration or evaluation process starts from the beginning in the new school district, causing further delays in the evaluation process

The scope of this problem is large. There are currently 7,000 children in preschool special education across Long Island, meaning that these families successfully made it through registration, evaluation, and eligibility to receive services. This does not represent the number of children that went through the evaluation process and were deemed ineligible, nor the families that never pursued the process due to barriers; it can be inferred—and has been HMG-LI’s general experience—that children already receiving Early Intervention are less affected by this issue than those newly seeking services because they are helped to navigate the CPSE process. That is also true for families that were referred to HMG-LI and reflected in our data. While more vulnerable based on factors like family income, HMG-LI families are inherently more connected than those families that have the same risk factors but are attempting to navigate this process without assistance. Therefore, while HMG-LI serves families in need across Long Island and in an increasing number of school districts, there are families in great need that are not represented in the data and that are not being counted in any system.

“The hardest part was getting all the papers. There was too much—I told his doctor, fill out this paper and that, so it was so frustrating for me at the time.”

“One of the problems that we did have is that the majority of therapists only spoke English... So therefore, [child] wouldn’t really attend the phone calls or wouldn’t really understand what was going on so that’s when they would reach out to [HMG Bilingual Family Resource Specialist] in order for [her] to help out.”

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7 Based on responses to outreach to the Family and Community Engagement (FACE) centers across the state.
What is the process that parents experience?

To understand the breadth of the problems with requesting an evaluation from school districts on Long Island for children 3-5 years-old, we identified 5 school districts frequented by the families we serve, along with 5 other school districts that were in wealthier neighboring school districts. Posing as parents concerned about our 3-year-old’s development, we asked to be taken through the steps to obtain an evaluation. We called in both English and Spanish. The results are as follows:

**Registration**
- 6 school districts have online only registration; 3 school districts do not; 1 allows families to choose online or paper
- 5 school districts require an appointment to verify registration after registration paperwork is completed; 2 school districts do not; and it is unclear for 3 school districts
- 7 school districts require a notarized lease or affidavit proving residency. One requires a tax or mortgage statement from the landlord in addition to notarized lease
- No school districts mention a notary available in school district offices
- In addition to a notarized lease, affidavit, or housing agreement, each school district required a number of other additional documents such as utility/cable bills or bank statements:
  - Excluding notarized documents mentioned above, additional documents included:
    - 2 additional proofs of residence required by 7 districts
    - 3 proofs required by 2 school districts
    - 4 proofs required by 1 school district

**Spanish Language**
- 3/10 had a Spanish language option on their phone line
- 6 had Spanish-speaking staff available, 4 did not respond
- 8 have paperwork available in Spanish; 2 unclear

**Other**
5 school districts required multiple phone calls before meaningful contact, and 1 did not result in any meaningful contact (mirroring the experience of HMG’s families attempting to connect with that district)

**Requesting Evaluation**
- 9/10 school districts require registration first; 1 did not mention registration
- Once school district registration is complete the preschool special education process requires additional paperwork not included in our analysis
The results of our analysis demonstrate major equity issues in accessing services for children with disabilities, which is a family’s legal right in both federal and state law. The biggest roadblocks are related to school registration, which, for some families, can delay the rest of the process by months. While our sample size did not show any meaningful difference in the extent of the registration requirements based on school district’s relative wealth, the barriers are bigger for those who rent their homes or have complicated housing situations, do not read/write fluently in English, cannot afford to take time off work, and do not have reliable access to transportation. These barriers are more common among low-income and BIPOC families and would have the same impact regardless of school district.

Because preschool special education is paid for through the county’s Department of Health, if the registration process reveals that the family lives in a different school district in the county, the money paid by the county’s Department of Health remains the same. However, the legal liability to provide evaluation in the mandated timeframe—and re-evaluations as needed—belongs to the district, and this can understandably underpin the desire to have families register first. The legal requirement that allows a school-aged child (over 5 years old) to start school immediately without first registering does not appear to apply to preschool special education.

We worked with a number of partners to find specific guidance on the registration and preschool special education evaluation request process but were not able to identify any. If Long Island school districts were to accept requests for evaluation while simultaneously beginning the registration process, it would save months of precious time for the families that need the most support. Fortunately, the average time for receiving an evaluation once the request was accepted was 51 days which fell within the 60 days legally mandated to complete evaluation. With specific efforts to streamline the registration process, simultaneous registration could allow school districts to address the challenge of registration while meeting the IDEA mandates.

**Definitions**

**Committee on Preschool Special Education (CPSE)** a multidisciplinary team established in accordance with the provisions of the IDEA and NY Education Law that each school district in New York has to determine eligibility for and ensure administration of services for children ages 3-5

**Individuals with Disabilities Education Act (IDEA)** a federal act that mandates services for children with special needs

**Part B** the part of IDEA that includes mandated services for 3-5 year-olds with disabilities. In New York, each school district’s CPSE manages Part B services

**Part C** that part of IDEA that mandates services for children under the age of 3 with developmental delays or disabilities. In New York, each county designates an Early Intervention Official who manage Part C services
Help Me Grow – Long Island was implemented in our region by a network of partners to help provide families with the extra support they need for equitable access to services, while promoting protective factors. The qualitative analysis demonstrates how we are fulfilling that purpose. With our current approach, we can indirectly address barriers by helping individual families overcome them. However, to ensure that all our young children thrive, we as a region must work together to address the systemic issues that are causing these barriers for families in the first place. This can be accomplished by continuing to:

- **Build-up and support parents’ voices:** Issues of CPSE evaluation requests were known by many of our stakeholders, and the experiences of families presented here helps illustrate the extent and importance of the problem for families. Families must be included as key stakeholders in developing a system of early childhood support on Long Island.

- **Utilize data collected by HMG-LI to identify and address inequities in early childhood.** If our community is truly committed to equity, we need to continue to look at and listen to the experiences of families across Long Island and then dig deep into the data to illustrate patterns and potential solutions. Preschool special education on Long Island is just one example where these types of barriers exist.

- **Expand the “grid” to reach more families.** When services are not coordinated into an interconnected grid, families can “slip through the cracks” in the system and fail to benefit from supports that exist in the community. HMG-LI helps coordinate a connected grid to swiftly and efficiently link families with young children to services that can support them. Long Island can help us expand the grid by aligning current public funding streams with HMG-LI’s efforts and sharing information about HMG-LI with families and the professionals that serve them across the region.

As demonstrated in the CPSE example, providing information and one-on-one family assistance can only go so far. In conjunction with partners and leaders across Long Island, we present below a number of best practices that would impact the CPSE process for the neediest families and address the inequities revealed in this report. The solution that would bring the most clarity is guidance from the New York State Department of Education for school districts on how best to enroll and process requests for evaluation for families with children 3-5 years old not already enrolled in a school district. This guidance could:

- **Promote simultaneous enrollment and evaluation as best practice**

- **Clarify what would constitute an acceptable delay in registration prior to the initiation of evaluation process** (for example, for children in grades K-12, 2 days is acceptable)

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8 Similar guidance was used in 2015 in an effective effort to address school district registration issues experienced on Long Island around unaccompanied minors.
However, short of State Education guidance or regulation, there are steps that school districts on Long Island can take to address inequitable family access to CPSE evaluation. These include:

- **Allowing for simultaneous evaluation requests and school district registration:** By accepting requests for evaluation immediately, the 60 day “clock” can start on that process as the family gathers and submits the necessary documentation for registration and the evaluation is scheduled.

- **Language Access:** Improve language access during the registration process. Due to the population assisted by HMG-LI, our analysis concentrated primarily on Spanish-speaking families. However, different school districts have distinct and evolving language needs. Districts can re-evaluate their readiness to serve families that speak common languages on Long Island such as Spanish, Haitian-Creole, Mandarin, Hindi, Urdu, and Arabic during the registration process.

- **Notary Availability:** Notify all families that a Notary is available at the school district, and place a school district Notary at the registration office at least 1 day a week.

- **Internal Quality Improvement:** Establish a quality improvement process within each school district that includes tracking the number of parents who ask for an evaluation, are told to register, and how many of those parents complete registration as instructed and proceed with the CPSE process.

- **Hire Coordinators:** New York City supports families that are seeking CPSE evaluations with coordinators that assist families in navigating the process. Individual school districts could replicate this practice or collaborate with community entities like HMG-LI to help families.

- **Alignment of school district requirements:** School districts across the region can adopt basic, similar requirements for registration, creating a “common app” to enroll children in school.

There are numerous things that other interested stakeholders can do to address the issues outlined in this report, including:

- **Detecting and referring for developmental concerns before age 3:** The problems delineated in this report are more burdensome for those families that are pursuing services to address a delay or disability for the first time. Families that identified a delay before age 3 and entered the Early Intervention system have the support of an Early Intervention Service Coordinator in making the transition. Although some delays are not evident during the first three years of life, many are, but are either undetected or resolved with a “wait and see” approach. This is an equity issue, as Black and Hispanic children are 44% and 78% less likely, respectively, to have delays identified and receive services than their white peers. As a region, if we better promote developmental milestones, screen for delays, and refer before a child turns 3, we could better ensure timely receipt of services.

- **Creating user friendly guidance for families on Long Island to address the CPSE process:** A step-by-step guide for Long Island families on navigating CPSE could be created, based on examples from other regions like New York City. This resource should then be made available at every school district as well as other locations that families might frequent, including doctor’s offices and community-based organizations.

- **Partner with existing efforts to address the school district registration issue across Long Island that not only affects CPSE evaluation requests, but all families attempting to register their children K-12.** Many of these agencies involved in this effort assisted in reviewing this report and are listed on the back page.

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Foundations and individuals interested in promoting solutions that build cognitive, emotional and social capacities of young children can invest in the growth of the HMG-LI collective impact partnership of agencies that serves as a safety-net for vulnerable children. Contact Melissa Passarelli, Director of Programs at Docs for Tots, for more information about funding and partnering opportunities: melissa@docsfortots.org

This work was supported in part by the Early Childhood Comprehensive Systems (ECCS) Impact grant awarded to the New York State Council on Children and Families by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling $2,122,300 over five years (from 2016 to 2021). The contents are those of the authors and do not necessarily represent the official views of, nor an endorsement, by HRSA HHS or the U.S. Government.

Quotes have been edited for clarity and names have been changed where applicable.