

# Developmental Delays in Young Children in Bedford- Stuyvesant and East Harlem: How Parents Respond



A Neighborhood Report by the Brooklyn and East  
and Central Harlem District Public Health Offices  
and Healthy Start Brooklyn



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## Key Findings

1. Parents understand their child’s development against the backdrop of their own experiences, not against milestones recognized by health professionals.
  - Parents may not be aware of their child’s developmental delays, resulting in missed opportunities to receive needed services.
2. As parents face their child’s developmental delays, they often blame themselves—thinking something they did or passed on caused the delays.
3. Parents whose child has developmental delays may encounter both support and skepticism when they turn to family, friends and their pediatricians for assistance.
  - These mixed messages often hinder—or even prevent—parents from obtaining services.
4. Parents point to a lack of access to adequate services and information, and discrimination against children with developmental delays and disabilities, as obstacles to receiving services for their child.

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### Editorial

Lise Millay Stevens, Editor; Deputy Director, Publications

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## This Report

For parents, watching their children grow and develop is deeply rewarding. While all young children develop differently, there are recognized milestones of child development that health care professionals use to track children's progress. When children do not reach these milestones in speech, physical movement, learning or social interactions, it may be a sign of developmental delays. Dealing with these delays can pose tough challenges for parents as they struggle to understand their children's special needs and try to make the best decisions for them.

Developmental delays and disabilities occur in about 15% of children in the United States, but are identified in only 30% of these children before they start school.<sup>1</sup> School-aged children with developmental disabilities typically have more doctor visits and school absences, and are more likely to repeat grades.<sup>2,3,4,5</sup> Poor children are at greater risk for developmental delays;<sup>\*6</sup> therefore, outreach efforts are best directed at low-income families. The earlier children with delays are identified and receive services, the greater their chance for improvement.<sup>7</sup>

The **Early Intervention Program** (EI), a government-funded program administered by the New York City Department of Health and Mental Hygiene, offers support and therapy to young children (infants to three-year-olds) who have developmental delays or disabilities. This free program provides individualized treatment plans for each child's unique needs.

This report explores how parents think about and experience their children's development, and examines the influence of family, friends, pediatricians and others in shaping parents' experiences with developmental delays. The goal of the report is to promote greater understanding of delays and to increase awareness among low-income families of the benefits of EI services.

## Study Methods

Researchers conducted interviews among 30 families in Bedford-Stuyvesant and East Harlem, with children who have potential or identified delays. From June to October 2006, 32 parents and caregivers participated in the study, including 23 mothers, four fathers, four foster mothers and one grandmother.

Most participants were stay-at-home parents; others worked outside the home as teachers, secretaries, home health-aides, waitresses, housekeepers and customer service representatives. Parents and caregivers ranged from 19 to 58 years of age; the age range of their 31 children was three months to three years. Most of the children had developmental delays in one or two developmental domains (see **box** below) and were participating in the EI program.

### Child Development Domains

**Cognitive:** How children learn, remember and play

**Communication:** How children combine and coordinate words and gestures

**Physical/motor:** How children move and manipulate objects

**Self-help/adaptive:** How (for example) children signal hunger and dress themselves

**Social-emotional:** How children interact with others and express feelings

\* Other risk factors for developmental delay include low birth weight, growth deficiency, elevated blood lead levels, family history of hearing or vision impairment, and parental drug or alcohol abuse.

## 1. Parents understand their child’s development against the backdrop of their own experiences, not against milestones recognized by health professionals.

Health professionals track early childhood development using established milestones. Many parents, however, use their own childhood experiences or those of other family members to assess their child’s progress. Other parents have an individualized view of child development, believing that each child is different and develops at his or her own pace; these parents often consider established developmental milestones less indicative of their child’s progress. Still other parents use a “good baby” assessment—if their child is eating, sleeping and not fussy, then he or she is doing well.

***“You know, you watch them grow. By having our other children, you basically get an idea about when they’re supposed to start sitting up, roll over, speak their first words, their first walk.”***

– a 50-year-old father of four

Overall, parents who use milestones that diverge from established ones—or do not use milestones at all—may not recognize developmental delays in their child, resulting in missed opportunities to receive needed services.

## 2. As parents face their children’s developmental delays, they often blame themselves—thinking something they did or passed on caused the delays.

Most parents react to their child’s developmental delay with guilt, fear and a sense of helplessness. They initially equate a delay with mental retardation, although the vast majority of children who receive EI services have less severe delays. A 24-year-old mother expressed her fears of how delays would affect her child: “My child on a yellow bus, being labeled as retarded, being made fun of, and there’s nothing I can do about it.” Other parents respond to their child’s delays by denying the problem exists, particularly in the first year of a child’s life.

***“Whatever is wrong, it’s my fault. And, I think that was the hardest part for me as far as seeking help, like I caused this.”***

– A 34-year-old mother of four

Parents often blame themselves for their child’s delays, pointing to their own personality traits (a quiet demeanor) or activities (poor eating habits during pregnancy) as reasons. Others are baffled by the problem and remain unclear about the causes. Still others identify external circumstances, such as vaccinations or hospital treatment of their infant, as causes of delays.

For many parents, there are often early clues about delays, although it usually takes time for them to deal with the problem—typically a lag of three to eight months.

### 3. Parents whose children have developmental delays may encounter both support and skepticism when they turn to family, friends and their pediatricians for assistance.

When parents face the possibility that their child is developmentally delayed, they often seek advice from trusted people in their lives—their partners, family members, friends, pediatricians and others. Some are deeply supportive and encourage parents to seek assistance, while others dispute the existence of the delays or the need for services, arguing that a child should be left to grow at his or her own pace. Still others may counsel parents to conceal their child’s delay to avoid stigma or labeling.

Sources of information for parents such as child development books, television talk shows and Web sites often identify pediatricians as the most important resource for parents of children with potential developmental delays. Although many parents take their concerns to their pediatricians, others do not, reporting previous negative experiences. Still others think it is inappropriate to reach out to pediatricians because delays are “social” and not “health” issues.

Parents generally encountered mixed messages of support and skepticism from the people in their lives, which often hindered or even prevented them from obtaining services for their children.

***“I tend to be the worry wart; my husband isn’t. And he is like, ‘Oh, you know, he’ll [their son] improve in time.’ And then I find out to be right. And I got, you know, like bittersweet. I mean, do I feel good that I was right? No. But I mean, again, I knew something, it just wasn’t right.”***

– A 33-year-old mother of two talks about her husband’s response to her suspicions about their son

### 4. Parents point to a lack of access to adequate services and information, and discrimination against children with developmental delays and disabilities, as obstacles to receiving services for their children.

In their neighborhood, parents point to obstacles such as social inequities and a lack of access to adequate information about developmental delays as reasons for not receiving services. As a 33-year-old mother of two explained, “There’s a social, economic, you know, component to all this, too. We just don’t have access to the same information. I think sometimes it’s a lack of knowledge. And I think that, you know, there’s a certain intimidation. Our pediatricians treat us differently. Even the way sometimes people talk to us differently.” Parents feel that medical and social service providers need to play a more active role in screening their children for potential delays and referring them to EI services.

Parents also suggested that discrimination against children with developmental delays and disabilities is widespread in their neighborhood. Because EI service providers typically work with children in their homes, parents are concerned that neighbors might observe these visits and spread rumors. Despite this concern, many parents did seek assistance and have observed positive changes in their child over time. These parents have come to see EI as a source of practical and emotional support, and a great benefit to their child’s ongoing development.

***“What do you mean these people [EI service providers] are coming to my house? They’re [neighbors] going to think something is wrong with my child. But once I saw my son growing within the program, it didn’t matter, because I knew I was doing what was best for him. It was just as much help for me as it was for him because I learned another way to help my son. And I think it brought me and my son closer.”***

– a 34-year-old mother of four

## Recommendations

We recommend that staff of community programs, health care and day care sites, community-based organizations and city agencies do the following:

### Screen children for developmental delays at regular intervals and refer at-risk children to be evaluated or monitored.

#### • Screening

- **In clinical settings**, screen children using a recommended tool at well-child visits, particularly the nine-month, 18-month and 30-month visits. Call 311 to refer a child with suspected delays for an EI evaluation. If a provider **strongly suspects** a child has a developmental delay, contact the borough office for an evaluation. (See back cover for contact information.)
- **At community program and child care sites**, screen children using the Ages and Stages Questionnaire (ASQ) to determine if referral to EI for evaluation is useful; call 311. Engage parents about child development, delays and EI services. (See back cover for ASQ contact information.)

#### • EI Developmental Monitoring Program

- Children at risk for delays, but who may not currently meet diagnostic criteria, are tracked.
  - Developmental risk criteria include low birth weight, failed initial hearing screening and elevated lead levels.
- Once a referral is made through 311, EI works with the family to monitor the child's progress, by mail or phone.
- If screenings suggest atypical development, the child will be referred to EI for further assessment.

### Educate parents about children's developmental milestones, delays and EI services, and provide advocacy tools.

- **Set expectations for milestones.** Talk with parents about milestones and what they should anticipate in the coming months of their child's development.

#### • Provide parents with tools, such as:

- **A developmental checklist.** Give parents a developmental checklist for milestones (e.g., "at six months, eight months, etc., your child should be able to..."), including warning signs of possible developmental delays, so they can monitor their child's development. If they observe delays, instruct parents to follow up with their provider.
- **Child activity and history diary.** Recommend that parents keep a journal to track their child's activities and record information concerning their child's birth history, immunization status and hearing and vision check-ups.
- **Question list for parents to pose to doctors and other service providers.** Provide parents with key questions to ask their health and social service providers about delays, developmental domains, etc.

- **Introduce EI.** Promote EI as a part of early child wellness, and familiarize parents of at-risk or delayed children with the entire EI process, from evaluation to services. Focus on the positive, enriching experiences of participating families.

## References

1. New York City Department of Health and Mental Hygiene. Burns B, Clancy J, Amgott M, et al. Identifying and referring children with developmental delays to early intervention services. *City Health Information*. 2008;27:9-16. [www.nyc.gov/html/doh/downloads/pdf/chi/chi27-2.pdf](http://www.nyc.gov/html/doh/downloads/pdf/chi/chi27-2.pdf). Accessed November 12, 2008.
2. Boyle C, Decoufle P, Yeargin-Allsopp M. Prevalence and health impact of developmental disabilities in US children. *Pediatrics* 1994;93(3):339-403.
3. Cordero J, Greenspan S, Bauman M, et al. CDC/ICDL Collaboration Report on a Framework for Early Identification and Preventive Intervention of Emotional and Developmental Challenges. November 11, 2006. Available at: [www.icdl.com](http://www.icdl.com) or [www.cdc.gov/ncbddd/dd/](http://www.cdc.gov/ncbddd/dd/).
4. Rydz D, Srour M, Oskoui M, et al. Screening for developmental delay in the setting of a community pediatric clinic: a prospective assessment of parent report questionnaires. *Pediatrics (serial online)*. 2006;118(4):1178-1186. Available at: [www.pediatrics.org/cgi/content/full/118/4/e1178](http://www.pediatrics.org/cgi/content/full/118/4/e1178).
5. Committee on Children with Disabilities (CCD). Developmental surveillance and screening of infants and young children. *Pediatrics*. 2001;108(1):192-195.
6. SRI International. Early intervention for infants and toddlers with disabilities and their families: participants, services, and outcomes. Final Report of the National Early Intervention Longitudinal Study (NEILS). January 2007. [www.sri.com/neils/pdfs/NEILS\\_Report\\_02\\_07\\_Final2.pdf](http://www.sri.com/neils/pdfs/NEILS_Report_02_07_Final2.pdf). Accessed November 11, 2008.
7. Centers for Disease Control and Prevention. Simpson G, Colpe L, Greenspan S. 2003. Measuring functional developmental delay in infants and young children: Prevalence rates from the NHIS-D. *Paediatric and Perinatal Epidemiology*, 17: 68-80.

Please use this form for referring families to EI. If you have any questions, call 311.

# NYC Health Early Intervention Program Referral Form

FOR OFFICE USE ONLY

Date of Referral: \_\_\_/\_\_\_/\_\_\_  
 EI ID #: \_\_\_\_\_  Re-Open

1. REQUIRED INFORMATION

<b>CHILD'S NAME</b> (Last, First, Middle)		<b>DATE OF BIRTH</b> (MM/DD/YY) ___/___/___	
<b>Sex</b> <input type="checkbox"/> Male <input type="checkbox"/> Female	<b>CHILD'S ADDRESS:</b> (Street, Apt. No)		<b>CITY</b>
<b>MOTHER'S NAME</b> (Last, First, Middle)		<b>TELEPHONE</b>	
<b>Caregiver or Alternate Contact Name</b> (Last, First)		<input type="checkbox"/> Home (____) ____-____	
Telephone (____) ____-____		<input type="checkbox"/> Cell (____) ____-____	
<b>Relation to Child</b> <input type="checkbox"/> Father <input type="checkbox"/> Grandparent <input type="checkbox"/> Foster Parent <input type="checkbox"/> Other, Specify:		<input type="checkbox"/> Work (____) ____-____	
<b>REASON FOR REFERRAL</b> (check only one)		<b>Person Presenting Referral to Early Intervention</b>	
<input type="checkbox"/> <b>EARLY INTERVENTION: Child with a suspected or known developmental delay or disability.</b> Fax to the EIP Regional Office in the child's borough of residence: Bronx (718) 410-4504 Brooklyn (718) 722-2998 Manhattan (212) 487-7071 Queens (718) 271-6114 Staten Island (718) 420-5360		Name	
<input type="checkbox"/> <b>DEVELOPMENTAL MONITORING: Child is developing typically but may be "at risk" for atypical development, or child missed or failed newborn hearing screening (not re-screened within 75 days).</b> Fax to the Child Find Office: Citywide (212) 227-3642		Agency or Facility, if any	
		Address (Street, Apt. No)	
		City, State, Zip	
		Telephone _____ Fax _____ (____) ____-____ (____) ____-____	
		Referral Source Type: <input type="checkbox"/> Community Program or EI Agency <input type="checkbox"/> Parent/Family <input type="checkbox"/> Foster Care/Other ACS <input type="checkbox"/> PCP <input type="checkbox"/> Hospital <input type="checkbox"/> Other (Specify):	
		<b>Comments</b>	

2. WITH INFORMED PARENTAL CONSENT

<b>RACE</b> <input type="checkbox"/> White <input type="checkbox"/> Asian <input type="checkbox"/> Black <input type="checkbox"/> Native American or Alaskan <input type="checkbox"/> Native Hawaiian/Other Pacific Islander	<b>ETHNICITY</b> <input type="checkbox"/> Hispanic <input type="checkbox"/> Not Hispanic	<b>MOTHER'S DATE OF BIRTH</b> (MM/DD/YY) ___/___/___	<b>PRIMARY HOME LANGUAGE</b>	<b>CHILD KNOWN TO ACS</b> <input type="checkbox"/> Yes <input type="checkbox"/> No
<b>CHILD'S DOCTOR</b>		<b>DOCTOR'S TELEPHONE</b> (____) ____-____		
<b>BIRTH HOSPITAL</b>		<b>LOCATION</b>		
<b>BIRTH WEIGHT</b> Pounds: _____ Ounces: _____ <b>OR</b> Grams: _____		<b>DIAGNOSIS</b> if known: _____		

3. REQUIRES PARENTAL SIGNATURE

**HEALTH INSURANCE COVERAGE INFORMATION**

I am insured by \_\_\_\_\_ under policy number \_\_\_\_\_. I consent to the inclusion of this insurance information in this referral to the New York Department of Health and Mental Hygiene for Early Intervention services for my child. I understand that no services will be billed to my insurance plan until services are authorized for my child.

**Only this section requires written parental consent.** Parent Signature \_\_\_\_\_ Date \_\_\_\_\_

<b>Request for ISC</b>		<b>FOR OFFICE USE ONLY</b> ISC Request Approved <input type="checkbox"/> Not Approved <input type="checkbox"/>	
Requested ISC	SC ID No.	Assigned SC	SC ID No.
Agency	ID No.	Agency	ID No.
Tel. (____) ____-____	Fax (____) ____-____	Tel. (____) ____-____	Fax (____) ____-____
Reason for ISC Request		Data Entry	Date ___/___/___

Questions? Dial 311 and ask for Early Intervention

EIP 01/09

Cut Along Dotted Line

## Provider Information

### NYC DOHMH Early Intervention

To refer families to Early Intervention, call 311 or the nearest borough office:

**Bronx:** 718-410-4110

**Queens:** 718-271-1003

**Brooklyn:** 718-722-3310

**Staten Island:** 718-420-5350

**Manhattan:** 212-487-3920

**EI referral form:** [www.nyc.gov/html/doh/downloads/pdf/earlyint/ei-referral-form.pdf](http://www.nyc.gov/html/doh/downloads/pdf/earlyint/ei-referral-form.pdf)

### Training about developmental delay and EI services

For presentations to groups by EI staff, call Kim Riley at 212-442-4764.

### City Health Information: Identifying and Referring Children with Developmental Delays to Early Intervention Services

[www.nyc.gov/html/doh/downloads/pdf/chi/chi27-2.pdf](http://www.nyc.gov/html/doh/downloads/pdf/chi/chi27-2.pdf)

### NYC DOHMH Developmental Monitoring Program

To refer children who are at risk for developmental delays, call 311.

An easy-to-complete screening tool will be sent to the parents of the at-risk child.

For more information:

[www.nyc.gov/html/doh/downloads/pdf/earlyint/dmu-doctor-brochure-online.pdf](http://www.nyc.gov/html/doh/downloads/pdf/earlyint/dmu-doctor-brochure-online.pdf)

### Provider tools

**American Academy of Pediatrics: developmental screening tools summary**

<http://aappolicy.aappublications.org/cgi/content/full/pediatrics;118/1/405/T1>

### DOHMH recommends Ages and Stages

**Questionnaires (ASQ):** It can be used at any well-child visit, for use with children between the ages of 4 to 60 months: Paul H. Brookes Publishing Co: 800-638-3775, and available at:

[www.brookespublishing.com/store/books/squires-asq/index.htm](http://www.brookespublishing.com/store/books/squires-asq/index.htm)

### Prompt sheets for providers to use with parents

[www.healthysteps.org/](http://www.healthysteps.org/) (see "Healthy Steps Materials")

### Developmental domains and milestones

University of Michigan Health Systems

[www.med.umich.edu/1libr/yourchild/devmile.htm#whatis](http://www.med.umich.edu/1libr/yourchild/devmile.htm#whatis)

## Parent Information

### NYC DOHMH Early Intervention

**Is my baby OK?** [www.nyc.gov/html/doh/downloads/pdf/earlyint/earlyint-ismybabyok-bro.pdf](http://www.nyc.gov/html/doh/downloads/pdf/earlyint/earlyint-ismybabyok-bro.pdf)

### Help your child get a great start

[www.nyc.gov/html/doh/downloads/pdf/earlyint/dmu-parent-brochure-online.pdf](http://www.nyc.gov/html/doh/downloads/pdf/earlyint/dmu-parent-brochure-online.pdf)

### Parent tools (including developmental checklists)

**The ABC's of Child Development**

[www.pbs.org/wholechild/abc/index.html](http://www.pbs.org/wholechild/abc/index.html)

### Learn the Signs, Act Early

[www.cdc.gov/actearly](http://www.cdc.gov/actearly). Call 800-CDC-INFO to receive a parent kit.

### NYS DOH developmental checklist

[www.health.state.ny.us/publications/0527.pdf](http://www.health.state.ny.us/publications/0527.pdf)

### Sharing concerns with doctors and other service providers

[www.firstsigns.org/concerns/parent\\_doc.htm](http://www.firstsigns.org/concerns/parent_doc.htm)

### Parent hotlines

**NYS DOH Growing Up Healthy 24-hour Hotline:**

800-522-5006

**Boys and Girls Town National Hotline**

24-hour hotline for any parenting problem: 800-448-3000

## Neighborhood Reports

To help reduce health disparities and improve the health of all New Yorkers, the New York City Department of Health and Mental Hygiene established **District Public Health Offices** (DPHOs) in 2003. These offices target public health efforts and resources to New York City neighborhoods with the highest rates of illness and premature death: North and Central Brooklyn, the South Bronx and East and Central Harlem.

An important part of our work is collecting and interpreting neighborhood health data. We hope this report fosters dialogue and collaboration among our many partners: other city agencies, community-based organizations, hospitals and clinics, businesses, and, most important, the New Yorkers who live and work in North and Central Brooklyn and East and Central Harlem. [For more information on the District Public Health Offices, visit: nyc.gov/health/dpho.](http://www.nyc.gov/health/dpho)

**Healthy Start Brooklyn** provides outreach, case management, education and training aimed at improving the health of women, infants and their families in Central Brooklyn. It is a collaborative effort of the NYC DOHMH, the Fund for Public Health in New York, SCO Family Services, Bedford-Stuyvesant Family Health Center and CAMBA.

[For more information on Healthy Start Brooklyn, visit www.fphny.org/p\\_healthy\\_start.php.](http://www.fphny.org/p_healthy_start.php)