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DEPARTMENT OF HEALTH

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Reissued
Early Intervention Memorandum 94-3

To: Early Intervention Officials
 Interested Parties

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Subject: Referral Procedures for the Early Intervention Program

The purpose of this memorandum is to provide clarification regarding the procedures to be followed by primary referral sources and early intervention officials to promote prompt, appropriate referrals of children to the Early Intervention Program, and coordination among all those with roles in the referral and intake process.

When and to whom must referrals be made?

The earliest possible identification of infants and toddlers with disabilities is a primary program objective. The Public Health Law (§2542.3) and program regulations (10 NYCRR §69-4.3, attached), require that primary referral sources must, *within two working days of identifying a child under age three as having a suspected or confirmed developmental delay or disability, or as at risk of having a disability, refer the child to the designated county official in the child's county of residence, unless the child has already been referred or unless the parent objects. Designated county official means the official designated by the municipality as responsible for receipt of referrals of children suspected of having or at-risk for developmental delays or disabilities (10 NYCRR §69-4.1(f)). Municipalities are required to designate either the early intervention official or the public health officer to receive all early intervention referrals (PHL §2542). If the public health officer is designated to receive referrals, and is not the early intervention official, he or she must promptly transmit the referral of children suspected of having a developmental delay to the early intervention official (10 NYCRR §69-4.2(a)(3)(i)). Attachment A is a listing by county of the designated county official to receive referrals.*

Children who are in foster care or who are homeless at the time of identification must be referred to the designated county official in the *municipality of current location* (PHL §2558, 10 NYCRR §69-4.15). *Municipality of current location* means the municipality in which a child lives which may be different from the municipality in which a child or the child's family lived at the time the local social service district assumed responsibility or custody for the child or family (PHL §2558(l)(c), 10 NYCRR §69-4.15(a)(3)).

Who makes referrals?

Pursuant to Section 2542 of Public Health Law and 10 NYCRR §69-4.3, the following primary referral sources are required to make referrals of children suspected of having or at risk of a developmental delay or disability to the early intervention official, *unless the child has already been referred or unless the parent objects*:

- all approved evaluators, service coordinators, and providers of early intervention services;
- hospitals;
- child health care providers;
- day care programs;
- local health units;
- local school districts;
- local social service districts;
- public health facilities;
- early childhood direction centers;
- operators of any clinic approved under Article 28 of Public Health Law, Article 16 of the Mental Hygiene Law, or Article 31 of the Mental Hygiene Law; and,
- all individuals who are qualified personnel as defined in PHL Section 2541(15) and at 10 NYCRR §69-4.1(aj) .

Parents may refer their children to the Early Intervention Program at any time via telephone, in writing, or in person (10 NYCRR§ 69-4.3(c)).

On what basis should a referral be made?

Referrals by primary referral sources may be based on the results of a developmental screening, diagnostic procedure(s), direct observation and informed clinical opinion of the child's developmental progress, or identification of factors which place the child at risk for developmental delay or disability. A primary referral source may also initiate a referral based on parent report of information concerning their child which may be indicative of a delay, or if a parent requests a referral.

Who must be referred?

Two categories of infants and toddlers must be referred to the Early Intervention Program unless the parent objects: (1) children suspected of having a disability; and, (2) children at risk of disability.

Who are the children suspected of having a disability?

Section 2541(5) of the Public Health Law defines disability as meaning a developmental delay or a diagnosed physical or mental condition with a high probability of resulting in developmental delay, such as Down Syndrome or other chromosomal abnormalities, sensory impairments, inborn errors of metabolism, or fetal alcohol syndrome. Additional examples of conditions with a high probability of developmental delay are provided in regulation at 10 NYCRR §69-4.3(e)(attached). Children with a diagnosed physical or mental condition with a high probability of delay are automatically eligible for the Early Intervention Program, whether or not they have a suspected or confirmed delay at the time of identification.

Who are the children "at risk" of disability?

In the Early Intervention Program, the term "at risk" describes children who are not suspected of having a disability and do not have a diagnosed condition with a high probability of delay, but are at increased risk of developmental delay because of specific identified biomedical or other risk criteria (PHL §2541(1), 10 NYCRR 69-4.3(f)).

Criteria are established in regulation for children at risk of having a developmental delay (see attachment B, 10 NYCRR §69-4.3(f)). The criteria include medical/biological neonatal, post-neonatal and early childhood criteria that place a child at risk for developmental delay. Primary referral sources may also consider social and environmental risk factors in the decision to make a referral, such as no prenatal care, parental developmental disability or diagnosed serious and persistent mental illness, parental substance abuse, lack of well child care or significant delay in immunizations (10 NYCRR 69-4.3(g)).

What services are children at risk of disability eligible to receive under the Early Intervention Program?

Section 2542 of the Public Health Law requires the Department of Health to develop a child find system that provides for the identification, location, tracking, and screening of children at risk of developmental delay, using resources available through a variety of programs and such other available resources as the Commissioner of Health commits for this purpose. These programs include: Part B of the federal Individuals with Disabilities Education Act, including the Early Childhood Direction Centers; Maternal and Child Health Programs under Title V of the Federal Social Security Act, the Infant-Child Health Assessment Program, the Medical Assistance Program's Early Periodic Screening, Diagnosis, and Treatment Program (New York State's Child-Teen Health Plan), and the Federal Supplemental Security Income Program.

The early intervention official is required to provide for the identification, tracking, and screening of children at risk of disability using these resources and other resources the Commissioner of Health commits for this purpose (10 NYCRR §69-4.2(a)(3)). The objective of tracking and periodically screening children who are at risk of disability is to be able to identify as early as possible those children who manifest a disability, in order to be able to provide them with appropriate early intervention services.

Primary health care providers are an important resource for screening at-risk children. At-risk children should have a "medical home" with a consistent primary health care provider who can provide them with comprehensive health care services, including routine developmental surveillance and periodic developmental screening.

The parent of a child referred as "at risk" of a disability has the right to request and receive a multidisciplinary evaluation if the parent believes the child has a disability.

What type of information must be transmitted in making a referral?

Information that must be transmitted by a primary referral source in referring an infant or toddler suspected of having a disability or at risk of developing a disability is defined in regulation (10 NYCRR §69-4.3(b)). Unless a parent objects to the referral, the following identifying information must be included as part of the referral:

- the child's name, sex and birth date;
- the name, address, and telephone number of the parent and, if known, both parents, including, if applicable, the person in parental relation;
- when necessary and applicable, the name and telephone number of another person through whom the parent may be contacted;
- whether the child is at-risk of developing a disability or has a suspected / confirmed delay; and,
- name and telephone number of the primary referral source.

Transmittal of any further information requires written parental consent. For example, information pertaining to the suspected disability or the criteria which place a child at risk may only be transmitted to the designated county official with written parental consent. Transmittal of such supplemental information assists the designated county official in processing the child's referral.

Primary referral sources may use already-existing consent forms or protocols to obtain consent to transmit information in addition to personally identifying information during a referral. Primary referral sources are responsible for ensuring the confidentiality of all information transmitted at the time of referral. Program regulations (10 NYCRR § 69-4.17(c)(1)) prohibit the disclosure by any officer or employee of the Department of Health, state early intervention service agencies, municipalities, evaluators, service providers, or service coordinators of any personally identifiable data, information, or records pertaining to an eligible child to any person other than the parent of such child.

How should a referral be made?

Primary referral sources and parents may make referrals to the designated county official by telephone, in writing, or in person. Primary referral sources should contact their early intervention official (see attachment A) to ascertain the specific referral procedures that have been established within their municipality.

The attached form DOH-3803 *Referral Form for Children At-Risk or Suspected of Developmental Delay or Disability or With a Confirmed Disability* may be used by primary referral sources to make referrals to the designated county official. Use of the DOH-3803 Referral Form is not required in order to make a referral. This form has been developed as a resource for municipalities and primary referral sources in facilitating the referral process. The form may be obtained from the New York State Department of Health Early Intervention Program or from early intervention officials, and may be copied.

What are the other responsibilities of primary referral sources?

The primary referral source must inform the parent of a child with a suspected or confirmed delay that their child will be referred to the early intervention official in the child's county of residence for a multidisciplinary evaluation (unless the parent objects) provided at no cost to the parent to determine eligibility for services, and that the referral does not obligate the parent to accept any services in the program (10 NYCRR 69-4.3(a)(1)). Primary referral sources must also provide the parent of a child with a suspected or confirmed delay with information about the Early Intervention Program, including a general explanation of the services available under the program, and the potential benefits to the child's development and the family of accessing those services.

Whenever feasible, all information must be provided in the parent's dominant language or other mode of communication (10 NYCRR 69-4.3(a)(1)(iii)). An *Early Help Makes A Difference* brochure, a supply of which is provided to every municipality by the Department of Health, should be provided to the parent to supplement the verbal explanation. Brochures are printed in English, Spanish, French, Chinese, Arabic, Hmong, Italian, Japanese, Greek, Korean, Kymer, Laotian, Russian, Vietnamese, and Yiddish.

Municipalities have established processes for triaging referrals. After the receipt of a referral of a child at risk of delay by the early intervention official, the referral may be directed to the Infant-Child Health Assessment Program. If the child has a suspected or confirmed delay, the early intervention official must designate an initial service coordinator. All parents should be informed that their child can receive a multidisciplinary evaluation at no cost to the parent if the parent believes the child has a developmental delay.

When an initial service coordinator is designated, he or she will contact the parent, provide further explanation about the program and provide the parent with options for obtaining a comprehensive multidisciplinary evaluation. The initial service coordinator will arrange for the evaluation or assist the parent in doing so. The parent may select an evaluator from the list of approved evaluators (10 NYCRR §69-4.8(a)(1) (2)). In the event that a parent directly contacts an approved evaluator for an evaluation, the evaluator must immediately notify the early intervention official in writing of the parent's selection (10 NYCRR §69-4.8(a)(1)). The approved evaluator may proceed with the evaluation with written parental consent no sooner than four days after such notification, unless otherwise approved by the initial service coordinator (10 NYCRR §69-4.8(a)(1)(i)).

What steps should be taken when a parent objects to a referral?

In those instances where a parent objects to the referral of their child, the parent must be provided with the name and telephone number of the early intervention official in the event that the parent may wish to contact the early intervention official in the future.

Primary referral sources are also required to make reasonable efforts, within two months of the objection, to follow-up with parents who have objected to a referral and, if appropriate, refer the child unless the parent continues to object. Written documentation of the parent's objection and follow-up actions taken by the primary referral source must be maintained (10 NYCRR 69-4.3(a)(3)).

What is the role of the Infant-Child Health Assessment Program (I-CHAP) in the Early Intervention Program?

Early intervention officials are required by regulation to provide for the identification, tracking and screening of children at risk of developmental delay, using available resources. One mechanism for carrying out this requirement is the Infant-Child Health Assessment Program (I-CHAP). I-CHAP (formerly IHAP) was initiated by the Department of Health in 1984 as a state-funded, county-administered effort to identify, locate, screen and track high-risk infants. In the fifty-seven counties outside New York City, county health departments are responsible for implementation of I-CHAP. In New York City, the City Department of Health provides policy direction and oversight to the Medical and Health Research Association, which operates the program.

Historically, public health nursing staff in each county have been responsible for identifying eligible children based on risk criteria noted on birth certificates or newborn hospital records. Public health nurses have also been responsible for: 1) enrolling young children and their families in the program; 2) ensuring periodic developmental screenings to assess the developmental and health status of enrolled children; 3) tracking and referring enrolled children to ensure needed services are received; 4) providing information to families about community-based health, mental health, social, and educational resources and services; and 5) providing necessary data to the state.

Recently, the Department has placed a stronger emphasis on enhancing coordination between I-CHAP activities and the local Early Intervention Program. I-CHAP activities include:

- determining the health insurance status of children;
- assisting families in enrolling in Medicaid or Child Health Plus;
- ensuring that children are engaged in a medical home and receiving ongoing developmental surveillance from their primary health care provider.

The New York City Infant-Child Health Assessment Program shares the statewide objectives for the program. Specifically, New York City I-CHAP seeks to ensure that at-risk children are referred to, engaged with, and receiving developmental screenings from appropriate primary health care providers. To accomplish these goals, New York City I-CHAP: (1) monitors the receipt of primary health care and developmental screening services by children referred to the program; (2) provides home visiting and follow-up services to children and families who are disengaged from primary health care in an effort to re-engage them in care; and, (3) provides training, support, and technical assistance to primary health care providers in the performance of developmental screenings.

With the implementation of the Early Intervention Program, I-CHAP staff have been responsible for ensuring those children identified by or to I-CHAP staff as having a disability are referred for a multidisciplinary

evaluation. Thus I-CHAP has a key role in the child find component of the Early Intervention Program, and in outreach and service delivery to the at-risk population.

How should hospitals and other health care facilities handle certain kinds of situations?

Hospitals and other health care facilities are responsible for referral and follow-up as described in this document. Many hospitals and health care facilities provide services to children from multiple counties. In making a referral of a child, hospitals must determine the child's county of residence and refer the child to the early intervention official in that county. Children who are homeless or in foster care must be referred to the municipality of current location, which means the county in which the child presently resides (PHL §2558(1)(c); 10 NYCRR §69-4.15(a)(3)).

There are situations where a child's prognosis or chance for survival is questionable. In these situations, the primary referral source should proceed with the referral once the child's condition is stabilized. If the child is transferred to another facility, the transferring facility should notify the receiving facility if a referral has been made. Otherwise, the receiving facility is responsible for making the referral to the designated county official.

With decreasing length of stays for new mothers and newborns in hospitals, some risk factors may be difficult for hospitals to identify. Other risk factors, however, including perinatally transmitted infections such as hepatitis B or prenatal alcohol or substance abuse, may be identifiable from patient records prior to discharge. Hospitals are responsible for referring only children with risks or established conditions identifiable prior to discharge.

What about follow-up information to the primary referral source?

With parental consent, primary referral sources may receive follow-up information about the outcome of a referral. The information shared with a primary referral source is within the parent's discretion and may range from a simple letter indicating the child and family are participating in the Early Intervention Program to documentation pertaining to the child's evaluation and Individualized Family Service Plan. There may be circumstances in which it is appropriate for the primary referral source (e.g., the child's primary health care provider if the child is medically involved) to be involved in the IFSP meeting or to provide information to contribute to the development of the IFSP. With parental consent, the child's primary health care provider may remain closely involved throughout the family's participation in the Early Intervention Program.

Out of State Referrals

Primary referral sources in New York State who have identified children with out of state residences at risk for or with a suspected delay or confirmed disability should contact the New York State Department of Health Early Intervention Program, 208 Corning Tower, Empire State Plaza, Albany, New York 12237. The Department of Health can make a direct referral to the Early Intervention Program in the child's state of residence or can provide the primary referral source with information about how to make such a referral.

Individuals with questions about referral procedures, or other aspects of the Early Intervention Program, should call the Department of Health at 518-473-7016.

Attachment A – The following link replaces a previous attachment that listed municipal/county contacts for the Early Intervention Program.

http://www.nyhealth.gov/community/infants_children/early_intervention/county_eip.htm

Attachment B - 10 NYCRR §69-4.3

Attachment C - DOH-3803 *Referral Form for Children At-Risk or Suspected of Developmental Delay or Disability or With a Confirmed Disability*

Attachment B – 10 NYCRR § 69-4.3

New York State Early Intervention Program Regulations

Sec. 69-4.3 Referrals

- (a) The following primary referral sources shall, within two working days of identifying an infant or toddler who is less than three years of age and suspected of having a disability or at risk of having a disability, refer such infant or toddler to the official designated by the municipality, unless the child has already been referred or unless the parent objects: all individuals who are qualified personnel; all approved evaluators, service coordinators, and providers of early intervention services; hospitals; child health care providers; day care programs; local health units; local school districts; local social service districts; public health facilities; early childhood direction centers; and, operators of any clinic approved under Article 28 of Public Health Law, Article 16 of the Mental Hygiene Law, or Article 31 of the Mental Hygiene Law.
- (1) A primary referral source who has identified an infant or toddler suspected of having a disability shall:
- (i) provide a general explanation of the services that are available under the Early Intervention Program and the benefits to the child's development and to the family of accessing those services;
 - (ii) inform the parent that, unless the parent objects, their child will be referred to the early intervention official for purposes of a free, multidisciplinary evaluation to determine eligibility for services;
 - (iii) whenever feasible, inform the parent about such referral in their dominant language or other mode of communication; and
 - (iv) ensure the confidentiality of all information transmitted at the time of referral.
- (2) A primary referral source who has identified an infant or toddler at risk of a disability shall:
- (i) provide a general explanation of the developmental screening, home visiting, and tracking services that are available to the family, including the Infant-Child Health Assessment Program, and the benefits to the child's development and to the family of accessing those services;
 - (ii) inform the parent that, unless the parent objects, their child will be referred to the designated county official for the purposes of developmental screening, home visiting, and tracking services, which may include enrollment in the Infant Child Health Assessment Program;
 - (iii) whenever feasible, inform the parent about such referral in their dominant language or other mode of communication; and
 - (iv) ensure the confidentiality of all information transmitted at the time of referral.
- (3) When a parent objects to the referral the primary referral source shall:
- (i) maintain written documentation of the parent's objection to the referral and follow-up actions taken by the primary referral source;

- (ii) provide the parent with the name and telephone number of the early intervention official if the child is suspected of having a disability or Infant-Child Health Assessment Program if the child is at-risk; and
 - (iii) within two months, make reasonable efforts to follow-up with the parent, and if appropriate, refer the child unless the parent objects.

- (b) Information transmitted in a referral from a primary referral source, for an infant or toddler suspected of having a disability or at risk of developing a disability, shall consist of only the following information, unless written consent is obtained from a parent to the transmittal of further information to the early intervention official:
 - (1) the child's name, sex, and birth date;
 - (2) the name, address and telephone number of the parent and/or if applicable, the person in parental relation to the child;
 - (3) when necessary and applicable, the name and telephone number of another person through whom the parent may be contacted;
 - (4) if the child is being referred because he or she is at risk of developing a disability, the referral shall include an indication that the child is not suspected of having a disability, but is at risk of developing a disability in the future; and
 - (5) name and telephone number of the primary referral source.

- (c) Referrals may be made at any time by parents via telephone, in writing or in person.

- (d) Referrals of children suspected of having a disability, which includes a developmental delay and/or a diagnosed physical or mental condition that has a high probability of resulting in developmental delay, shall be based on:
 - (1) the results of a developmental screening or diagnostic procedure(s); direct experience, observation, and perception of the child's developmental progress;
 - (2) information provided by a parent which is indicative of the presence of a developmental delay or disability;
 - (3) or a request by a parent that such referral be made.

- (e) Diagnosed physical and mental conditions with a high probability of developmental delay include:
 - (1) chromosomal abnormalities associated with developmental delay (e.g., Down Syndrome);
 - (2) syndromes and conditions associated with delays in development (e.g., fetal alcohol syndrome);
 - (3) neuromuscular disorder (e.g., any disorder known to affect the central nervous system, including cerebral palsy, spina bifida, microcephaly or macrocephaly);
 - (4) clinical evidence of central nervous system (CNS) abnormality following bacterial/viral infection of the brain or head/spinal trauma;
 - (5) hearing impairment (a diagnosed hearing loss that cannot be corrected with treatment or surgery);
 - (6) visual impairment (a diagnosed visual impairment that cannot be corrected with treatment (including glasses or contact lenses) or surgery);
 - (7) diagnosed psychiatric conditions, such as reactive attachment disorder of infancy and early childhood; (symptoms include persistent failure to initiate or respond to primary caregivers;

fearfulness and hypervigilance that does not respond to comforting by caregivers; absence of visual tracking); and

- (8) emotional/behavioral disorder (the infant or toddler exhibits atypical emotional or behavioral conditions, such as delay or abnormality in achieving expected emotional milestones such as pleasurable interest in adults and peers; ability to communicate emotional needs; self-injurious/persistent stereotypical behaviors).

(f) Referrals of children at risk of having a disability shall be made based on the following medical/biological risk factors:

(1) Medical/biological neonatal risk criteria, including:

- (i) birth weight less than 1501 grams
- (ii) gestational age less than 33 weeks
- (iii) central nervous system insult or abnormality (including neonatal seizures, intracranial hemorrhage, need for ventilator support for more than 48 hours, birth trauma)
- (iv) congenital malformations
- (v) asphyxia (Apgar score of three or less at five minutes)
- (vi) abnormalities in muscle tone, such as hyper- or hypotonicity
- (vii) hyperbilirubinemia (> 20mg/dl)
- (viii) hypoglycemia (serum glucose under 20 mg/dl)
- (ix) growth deficiency/nutritional problems (e.g., small for gestational age; significant feeding problem)
- (x) presence of Inborn Metabolic Disorder (IMD)
- (xi) perinatally- or congenitally-transmitted infection (e.g., HIV, hepatitis B, syphilis)
- (xii) 10 or more days hospitalization in a Neonatal Intensive Care Unit (NICU)
- (xiii) maternal prenatal alcohol abuse
- (xiv) maternal prenatal abuse of illicit substances
- (xv) prenatal exposure to therapeutic drugs with known potential developmental implications (e.g., psychotropic medications, anticonvulsant, antineoplastic)
- (xvi) maternal PKU
- (xvii) suspected hearing impairment (e.g., familial history of hearing impairment or loss; suspicion based on gross screening measures)
- (xviii) suspected vision impairment (suspicion based on gross screening measures)

(2) Medical/biological post-neonatal and early childhood risk criteria, including:

- (i) parental or caregiver concern about developmental status
- (ii) serious illness or traumatic injury with implications for central nervous system development and requiring hospitalization in a pediatric intensive care unit for ten or more days
- (iii) elevated venous blood lead levels (above 19 mcg/dl)
- (iv) growth deficiency/nutritional problems (e.g., significant organic or inorganic failure-to-thrive, significant iron-deficiency anemia)

- (v) chronicity of serous otitis media (continuous for a minimum of three months)
- (vi) HIV infection

(g) The following risk criteria may be considered by the primary referral source in the decision to make a referral:

- (i) no prenatal care
- (ii) parental developmental disability or diagnosed serious and persistent mental illness
- (iii) parental substance abuse, including alcohol or illicit drug abuse
- (iv) no well child care by 6 months of age or significant delay in immunizations; and/or
- (v) other risk criteria as identified by the primary referral source

(h) When the child is in the care and custody or custody and guardianship of the local social services district, the early intervention official shall notify the local social services commissioner or designee that the child has been referred.