



Reducing Risks:

Implementing the
Early Intervention
Program for Infants
and Toddlers in
New York City



CITIZENS' COMMITTEE for CHILDREN
OF NEW YORK INC.

Acknowledgements

Many policymakers and professionals generously supported this project with their time and expertise. We would like to thank them and note that the recommendations made in CCC's policy brief do not necessarily reflect those of the individuals listed. They include Sandra Ginsberg and Beverly Samuels, both of the New York City Department of Mental Health, Mental Retardation & Alcoholism Services (DMH, MR & AS) Early Intervention Program; Donna Noyes, Director of the New York State Department of Health (SDOH) Early Intervention Program; Linda

Silver, Director of Program Services of Little Meadows Early Childhood Center; and Margaret Raustiala, Deputy Executive Director of the InterAgency Council. We also want to thank the Early Intervention contract service providers who took time to meet with Citizens' Committee for Children of New York (CCC) volunteers as we conducted this research.

Finally, this project would not have been possible without CCC volunteers and to you we offer a special thank you.

Nancy F. Solomon
Chairman and
Task Force Co-Chair

Martha J. Olson, Esq.
President

Barbara Landau
Task Force Co-Chair

Gail B. Nayowitz
Executive Director

Lavita McMath
Staff Associate for Education and Child Care

LIST OF TASK FORCE MEMBERS

Orren Alperstein	Barbara Landau, Co-Chair
Ruth Feder	Sally Mendel
Carol Feinberg	Ann Sand
Donna Hardiman	Emily Satloff
Ruth Houghton	Beverly Schneider
Anne Jones	Jean Schrag
Nancy Locker	Nancy Solomon, Co-Chair

Conclusion

Family Life Does Improve after Early Intervention

Finally, we asked about the overall well-being of the children and their families upon completion of the EI Program. All of the agencies reported that children's quality of life improved after they finished receiving EI services. They found families better able to meet the needs of their young children with disabling conditions, because (1) parents had a better understanding of developmental delays and the social and emotional problems associated with them; (2) parents had accumulated knowledge about services available to address their child's needs; (3) parents began to

accept the child as he/she is; and (4) parents experienced less stress and depression after receiving the services. The agencies emphasized that the degree of parental involvement is directly related to positive outcomes for the child.

The Future of Early Intervention

Again, CCC findings indicate that parents, providers, and government officials are pleased with the program. The Early Intervention Program in New York City is working well, and with a few minor improvements will continue to provide quality services to children and families.

**CITIZENS' COMMITTEE FOR CHILDREN OF NEW YORK IS AN INDEPENDENT NON-PROFIT ORGANIZATION
THAT SEEKS TO ENSURE THAT EVERY CHILD IS HEALTHY, HOUSED, EDUCATED AND SAFE.**

CHAIRMAN

Nancy F. Solomon

PRESIDENT

Martha J. Olson, Esq.

VICE PRESIDENTS

James Krauskopf
Lee A. Link
Samuel P. Peabody
Elizabeth Sheehan
Heidi Stamas

TREASURER

Ernesto Loperena

SECRETARY

Alma J. Carten, D.S.W.

EXECUTIVE DIRECTOR

Gail B. Nayowith

BOARD OF DIRECTORS

Andrea H. Bates
Susan S. Benedict
Felice Burns
Helen S. Cooper
Judy Tobias Davis
Thelma Dye, Ph.D.
Mrs. Arthur A. Feder
Carol J. Feinberg
Edythe W. First
Diane A. Fogg
Gerald Goldsmith
Nancy Hoving
Bonnie L. Howard
Chris Stern Hyman, Esq.
Sr. Mary Paul Janchill, D.S.W.
Janet M. Johnson, Esq.
Mrs. E. Powis Jones
Michael G. Kalogerakis, M.D.
Sheila Kamerman, D.S.W.
Hamilton F. Kean, Esq.
Daniel Kronenfeld
Mrs. W. Loeber Landau
Frances Levenson, Esq.

Nancy Locker
Elinor G. Mannucci, Ph.D.
Sally Mendel
Sue Nager
Hermine Nessen
Alma E. Rangel
Natalia G. Ritter
Mrs. Edwin Robbins
John Sanchez
Ann S. Sand
Marge Scheuer
Joanne M. Stern
Linda Viertel
Darren Walker
Pat Wildman
Ruth A. Wooden

HONORARY DIRECTORS

Mrs. Howland Davis
Pam S. Levin
Charlotte Pratt
Mrs. Robert S. Siffert
Mrs. Jesse D. Wolff

CITIZENS' COMMITTEE for CHILDREN OF NEW YORK, INC.

105 East 22nd Street, 7th Floor
New York, NY 10010
V: (212) 673-1800 F: (212) 979-5063
E-mail: info@kfny.org
website: www.kfny.org

More Children Should Be Insured

In this area, we reviewed the adequacy and timeliness of payments and the percentage of children who are covered by some form of insurance (private, Medicaid, Child Health Plus) and those who are uninsured. Half of the agencies surveyed (5) were satisfied with the timeframe for reimbursement for EI services. The other half were dissatisfied with the timeframe and attributed their lengthy wait for reimbursement primarily to incorrect data entry.

Out of ten agencies, eight indicated that more than three-quarters of the children served were enrolled in Medicaid. Several knew the percentage of children enrolled in Child Health Plus which they estimated to range from 9%-20%. All agencies visited reported that the number of children uninsured ranged 2%-40%.

RECOMMENDATION: Our findings indicate high percentages of children enrolled in Medicaid, some uncertainty by the agencies regarding the percentages of children enrolled in CHP, some children covered by private insurance, and a portion of uninsured children. To ensure that all children have health insurance coverage which they need for healthy development and access to services, and to maximize funding for the Early Intervention Program, CCC recommends that service coordinators (1) determine whether a child has insurance

and what kind, and (2) receive training on Medicaid and CHP eligibility and enrollment with expectations that all eligible children in the family must be enrolled in some form of insurance.

Issues with the payment process and rate were raised at each site visited. Although, we do not have enough information to make a specific recommendation in this area, it might be beneficial to re-examine the reimbursement process. There may be opportunities for improvement perhaps through more sophisticated electronic processing mechanisms.

The Rights of Children and Families are Being Protected

The State regulations promulgate specific procedures to protect the rights of children and families such as impartial hearings and mediation. Our goal was to see if these processes were adequately explained to parents. We were pleased to find that all of the agencies utilized the Early Intervention Program Parent's Guide in English and Spanish to inform parents of their rights.

RECOMMENDATION: Because the parent guide provides clear and concise information, we believe it must continue to be updated and provided in other languages, especially Russian and Chinese, to every family whose child receives EI services.

Reducing Risks: Implementing the Early Intervention Program for Infants and Toddlers in New York City

In 1986 Congress amended the Education of the Handicapped Act, establishing Part H of the Individuals with Disabilities Act, formerly known as P.L. 99-457. This amendment offered states the option to develop comprehensive early intervention programs for infants and toddlers ages birth to three years with developmental delays and disabilities. The EarlyCare legislation, enacted in 1992, was New York State's response to the federal mandate. Citizens' Committee for Children of New York, Inc. (CCC) advocated for the passage of this landmark legislation, because it replaced the antiquated Family Court procedures for accessing special education services for very young children with disabilities with an entitlement for services and a more coordinated system that serves infants and toddlers in the context of their families. The legislation also provides support and guidance to families in partnership with professionals.

Early Intervention in New York City

The New York State Department of Health (SDOH) is the designated lead agency for the Early Intervention (EI) Program. SDOH is responsible for program oversight throughout the State, including developing regulations, setting provider reimbursement rates, and monitoring counties. In New York City, the Department of Mental Health, Mental Retardation and Alcoholism Services (DMH, MR & AS) is the lead agency that is responsible for the implementation of the program and monitoring of the providers.

In FY 1998-99, there were approximately 13,000 children referred to the EI Program in New York City. There are currently over 220 contracted EI providers. Services provided include evaluation, service coordination, special instruction, occupational, speech and physical therapy, psychological services, family training, counseling, assistive technology, and respite services.

COMPONENTS OF STATE EARLY INTERVENTION PROGRAMS AS REQUIRED BY THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT (P.L. 99-457)

1. Definition of developmental delay and eligibility;
2. Timetables to ensure the availability of appropriate early intervention services to eligible children;
3. Comprehensive, multidisciplinary evaluations of eligible children;
4. Individualized family service plans/case management services;
5. A comprehensive child find system;
6. A public awareness program to promote early identification and referral of eligible children;
7. A central directory of early intervention services, resources, experts, research, and demonstration projects;
8. A comprehensive system of personnel development;
9. A governor-designated state lead agency responsible for all administrative and programmatic aspects of the service system;
10. A policy for contracting or otherwise arranging for early intervention services;
11. A procedure for ensuring timely reimbursements of funds for service providers;
12. Procedural safeguards;
13. Policies and procedures to establish and maintain standards to ensure appropriate and adequate training of early intervention personnel; and
14. A system to compile data on the total number of eligible children, number receiving services and types of services provided within the state.

What We Did

In the Fall of 1998, CCC established an Early Intervention Task Force to study New York City's Early Intervention Program to determine if the implementation of the program conforms to State regulations and if the program's services have led to desired outcomes for children. During the planning stages of the study, CCC met with Donna Noyes, Director of the New York State Department of Health (SDOH) Early Intervention Program; Linda Silver, Director of Program Services of Little Meadows Early Childhood Center; Margaret Raustiala, Deputy Executive Director of the InterAgency Council; and Sandra Ginsberg and Beverly Samuels, both of the NYC DMH, MR & AS EI Program. Based upon these discussions, we focused our monitoring project on examining the following six regulatory components: (1) the Child Find System/Referrals; (2) Service Coordination; (3) Service Settings; (4) Payment Process/Rate Structure and Health Insurance; (5) Procedural Safeguards; and (6) Outcomes. Between February and May of 1999, CCC interviewed ten EI contract service providers. They included schools and agencies serving children with or at risk of developmental delays, a mental health agency, and a home health care agency. All offered EI services in a variety of settings: home-based, center-based, and preschools.

What We Found

Our findings confirm early anecdotal evidence of the overall success of the program. We found that children and families served in the programs we visited fare better after receiving EI services and that New York City service providers, as well as City and State government officials, were generally pleased with the design and management of the EI system. In this policy brief, we highlight our findings and offer several modest recommendations that may be useful in providing and meeting the increasing demand for quality early intervention services for very young children.

Not Enough Referrals from Medical Professionals

New York City data highlights the rapid increase in children referred to Early Intervention over its five year history. From 1994 to 1999, the number of children referred to EI grew from a reported 8,900 to 13,000 children, an increase of 46%. We wanted to gain an understanding of where referrals originate. In the programs we studied, we found that the majority of referrals came directly from parents, with hospitals and physicians providing the second largest source of referrals. Less frequently, referrals came from foster care agencies, early education programs, health clinics, and other social service agencies. While we found physicians to be the second largest source of referrals, EI providers reported concern about the low numbers of referrals from doctors, given their frequent contact with children and their families.

RECOMMENDATION: Medical and mental health professionals that provide primary and specialty care need to be aware of the early signs of developmental delays in order to make the quickest linkage to services. CCC recommends that information kits be distributed, at least annually, to medical professionals particularly pediatricians in managed care panels and Child Health Clinics, to aid in the identification of children at risk of developmental delays. The information kits should also explain how to refer children for EI assessments.

We also recommend that an EI outreach brochure be developed for parents/caregivers in several languages (English, Spanish, Chinese, and Russian) for wide distribution to facilities and programs that children and families attend. They should be available in foster care and other social service agencies, early education programs, public and private schools, Medicaid offices and Child Health Plus (CHP) enrollment sites, religious institutions, job centers, shelters, public housing developments, and Child Health Clinics which serve low-income and immigrant populations. Large posters should also be designed and distributed to advertise the Early Intervention program as well as descriptive signs that help define developmental delays.

Service Coordinators Need More Training

We sought to gain an understanding of the qualifications and skill levels of the EI Program's service coordinators. At all ten program sites, we found that the service coordinators were well educated and experienced. They were registered nurses and certified social workers that held master's degrees in public health or social work, and/or had several years of experience in the social services/mental health field. Two agencies indicated the need for multi-lingual staff in order to effectively communicate with families.

However, our survey revealed that the on-going training for service coordinators provided by the agencies was not consistent. According to our review fewer than half of the agencies (4) conducted training at least once a month, another three agencies conducted training only 2-4 times per year, with the remaining three providing no training at all, or training on an as-needed basis. The absence of on-going training limits the delivery of consistent, quality EI services to children and families.

RECOMMENDATION: Because the Early Intervention Program is experiencing rapid growth, the number of service coordinators needed is increasing simultaneously. Therefore, on-going training is essential to ensure quality. Although the New York State Department of Health is responsible for training, the agency does not provide it regularly. CCC recommends that the SDOH provide training or funds for New York City's Department of Mental Health, Mental Retardation, & Alcoholism Services to train all service coordinators so that they can have an understanding of the scope of the EI Program including regulations and services offered. Basic service coordinator training should be followed by bi-monthly sessions that would enhance their skills and keep them abreast of new initiatives and policies as well as related resources available in the community to meet family needs. Each EI provider and DMH, MR, and AS must be responsible for disseminating all up-to-date and pertinent EI Program information to the service coordinators.

Furthermore, to ensure that service coordinators adequately meet the needs of the children and families they serve, we recommend that agencies encourage the hiring of multi-lingual service coordinators in the communities where they are needed.

Parents Prefer Home-Based Services

We wanted to learn more about where families generally prefer to have their child's EI services delivered. For the sites we studied, the data revealed that the child's home was the most preferred place for EI service delivery. EI providers expressed a need for more monitoring of home-based services and for better parent information regarding the options offered by either home-based or center-based programs. They also noted that families with children receiving home-based services can be socially isolated.

RECOMMENDATION: Our review showed a skewing towards home-based service delivery. CCC recommends the development of regional support programs for parents whose children receive services at home to establish linkages with the larger EI provider community, family support, and advocacy community. Because most EI services are now being provided in the home, we also recommend increasing the monitoring of home-based services to ensure quality.

To address the lack of information about EI service delivery options, parents should receive detailed verbal and written information, developed by DMH, about the EI Program service delivery options from the service coordinator. As stated above, mandatory service coordinator training would help guarantee the accuracy and consistent availability of this information. There are benefits to both home-based and center-based services. Parents must have sufficient information to make the most developmentally appropriate choice for their child. While infants may be best served at home, for toddlers it may be more appropriate to combine home and center-based services to promote positive peer engagement and reduce family social isolation.

**CITIZENS' COMMITTEE FOR CHILDREN OF NEW YORK IS AN INDEPENDENT NON-PROFIT ORGANIZATION
THAT SEEKS TO ENSURE THAT EVERY CHILD IS HEALTHY, HOUSED, EDUCATED AND SAFE.**

CHAIRMAN

Nancy F. Solomon

PRESIDENT

Martha J. Olson, Esq.

VICE PRESIDENTS

James Krauskopf
Lee A. Link
Samuel P. Peabody
Elizabeth Sheehan
Heidi Stamas

TREASURER

Ernesto Loperena

SECRETARY

Alma J. Carten, D.S.W.

EXECUTIVE DIRECTOR

Gail B. Nayowith

BOARD OF DIRECTORS

Andrea H. Bates
Susan S. Benedict
Felice Burns
Helen S. Cooper
Judy Tobias Davis
Thelma Dye, Ph.D.
Mrs. Arthur A. Feder
Carol J. Feinberg
Edythe W. First
Diane A. Fogg
Gerald Goldsmith
Nancy Hoving
Bonnie L. Howard
Chris Stern Hyman, Esq.
Sr. Mary Paul Janchill, D.S.W.
Janet M. Johnson, Esq.
Mrs. E. Powis Jones
Michael G. Kalogerakis, M.D.
Sheila Kamerman, D.S.W.
Hamilton F. Kean, Esq.
Daniel Kronenfeld
Mrs. W. Loeber Landau
Frances Levenson, Esq.

Nancy Locker
Elinor G. Mannucci, Ph.D.
Sally Mendel
Sue Nager
Hermine Nessen
Alma E. Rangel
Natalia G. Ritter
Mrs. Edwin Robbins
John Sanchez
Ann S. Sand
Marge Scheuer
Joanne M. Stern
Linda Viertel
Darren Walker
Pat Wildman
Ruth A. Wooden

HONORARY DIRECTORS

Mrs. Howland Davis
Pam S. Levin
Charlotte Pratt
Mrs. Robert S. Siffert
Mrs. Jesse D. Wolff

CITIZENS' COMMITTEE for CHILDREN OF NEW YORK, INC.

105 East 22nd Street, 7th Floor
New York, NY 10010
V: (212) 673-1800 F: (212) 979-5063
E-mail: info@kfny.org
website: www.kfny.org