

Philadelphia's Early Intervention System

**Progress,
But Still Not Good
Enough for Our Kids**



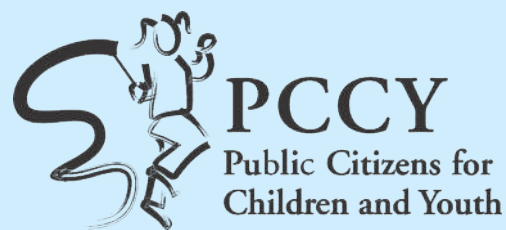
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Philadelphia's Early Intervention System: Progress, But Still Not Good Enough for Our Kids

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Executive Summary

Philadelphia's Early Intervention System: Progress, But Too Many Children Are Still Left Behind

Early Intervention is a powerful resource to help children with delays and disabilities achieve their full potential. The program provides a range of therapeutic and educational services to children and their families while they are young, reducing barriers to their independence and supporting school success. Outcomes are clear: Early Intervention reduces the need for special education and benefits children and their families in a host of ways. The program's economic value is compounded when Early Intervention is embedded in a strong, high quality early learning system, which is also shown to reduce the need for special education. In Pennsylvania, one study estimated that providing targeted preschool programs would reduce special education expenditures in the state by at least 8 percent annually; a typical school district could save 78 cents of every dollar spent on preschool education through savings in special education.¹

While every child with a developmental delay or disability is entitled to help from this program, many children in Philadelphia who could benefit from Early Intervention do not receive these services. The likelihood of developmental delays and disabilities is closely tied to known risk factors that include poverty, abuse or neglect, exposure to lead, low birth-weight and premature birth, and even low maternal education. In Philadelphia the combined level of risk would predict a high need for Early Intervention services – the highest in Pennsylvania. However, when we compared the rates of enrollment in Philadelphia vs. Pennsylvania's other major cities (where the risk is also elevated) we found that Philadelphia ranked lowest, not highest. Had Philadelphia performed at the rates of these other cities, up to 7,000 more children would have been helped.

Children are left behind because:

- they are never screened for developmental delays;
- they are screened but not referred to the program when a problem is identified;
- their parents feel stigmatized and do not understand the potential benefit to their child;
- the program creates barriers to entry or continuation that the family cannot negotiate; and
- there is too little affordable, inclusive, high quality early care and education which can complement the services in Early Intervention and produce better outcomes for children.

Executive Summary

In all of these cases, the Early Intervention system is failing a young child at the most critical time in her or his life.

The number of children served in Early Intervention in Philadelphia increased more than 40 percent over a six year period. The Preschool program grew even faster than the Infant/Toddler program. Several operational problems that created barriers to entry for infants and toddlers only a few years ago have been largely worked out. Even so, recent data showed that the program lost 35 percent of those who were referred because they were never evaluated. This gap should be closed.

Parents and advocates for preschool-age children continue to report a mix of responses, reflective of a system under pressure that struggles to provide consistent, quality services. Transitions between providers – from Infant/Toddler Early Intervention to Preschool Early Intervention and from Preschool to Kindergarten in the School District of Philadelphia – are the most difficult for parents to navigate and too often result in breaks in services that hinder children’s growth and learning. A bifurcated system, inherited from Early Intervention’s framework at the federal level, makes these transitions more cumbersome than is necessary.

To strengthen our system, we urge City, State and School District officials, healthcare providers and managed care systems, early childhood educators and community-based organizations to join together to:

- Build a stronger high quality early learning system that can help every child develop to her or his potential and be ready for school. Significantly increase the level of inclusive, high quality seats so that every child in Early Intervention – as well as those with milder delays – has the option to benefit from these programs, regardless of family income.
- Educate parents and caregivers about developmental milestones from birth to five, reduce the stigma associated with developmental delays, and spread the word about Early Intervention;
- Increase the capacity of child-serving professionals, including physicians and health systems, to provide information about Early Intervention, screen for developmental delays, refer, counsel parents and follow up as appropriate;
- Combine Infant/Toddler and Preschool services under a single entity to improve operations and streamline the age three transition process, reducing the attrition and interruptions in services that are too common today.
- Improve children’s and families’ experiences in the transition to kindergarten by starting earlier and providing more choices and better information to parents.
- Serve all families equitably by removing existing financial, systemic, linguistic and cultural barriers to access.

Early Intervention is based on what we know about the brain: the best time to address developmental concerns is when brain development is at its most intense, during a child's earliest years.

Research shows that Early Intervention works. The National Early Intervention Longitudinal Study (NEILS) followed a large sample of children who received Early Intervention as infants and toddlers. The final report found that when they reached kindergarten, 42 percent of them performed as well as other children in reading and math and did not need special education.²

The Early Intervention system is designed to screen young children for developmental delays, evaluate their needs and provide services to those who require them. It serves children from birth until they start school. Early Intervention is funded and regulated by both federal and state governments. The program's framework, derived from the Individuals with Disabilities Education Act (IDEA), provides for two separate tracks: the Infant/Toddler Early Intervention program serving

Eligibility for Early Intervention in Pennsylvania

Infants and Toddlers who have:

A significant delay in one or more areas of development;

OR

A specialist's determination that there is a delay even though it doesn't show up on the assessments (called informed clinical opinion);

OR

Known physical or mental conditions which have a high probability for developmental delays (such as Down Syndrome).

Preschoolers who have:

A significant delay in one or more areas of development compared to other children of the same age;

OR

Any of the following physical or mental disabilities: autism/pervasive developmental disorder; serious emotional disturbance; neurological impairment; deafness/hearing loss; specific learning disability; mental retardation; multiple disabilities; other health impairment; physical disability; speech impairment or blindness/visual impairment;

AND

Are in need of special education and related services.

from OCDEL, "Early Intervention Supports and Services: Facts for Families"

children from birth to their third birthdays and the Preschool Early Intervention program for children from three until they start school.³

In Pennsylvania, Infant/Toddler Early Intervention is funded through the Department of Public Welfare (DPW), while Preschool Early Intervention is funded through the Department of Education. However, the Office of Child Development and Early Learning (OCDEL) crosses both departments and administers both Early Intervention programs along with all early childhood programs. It is an unusual but effective model that has worked to bring these two previously disparate programs together and improve continuity between them.

Defining the Need

There are no national standards for what constitutes a developmental delay or disability; the definition is left up to the states to develop. However, using a definition similar to Pennsylvania's, it is estimated that nationally, as many as 13 percent of children from birth to three have delays or disabilities that would meet the eligibility requirements for Early Intervention.⁴ Yet only 2 to 3 percent of these children are receiving services. A Centers for Disease Control and Prevention-sponsored survey estimates that one in six children age three and over has a delay or disability and notes that a majority of developmental delays are not identified until children start school.⁵

For children under the age of three, Pennsylvania defines eligibility as having a significant developmental delay, determined in one of three ways: that is greater than 25 percent of the expectation for a child's age; testing 1.5 standard deviations below the norm in at least one main developmental area; or having a health condition that increases the risk of delay;⁶ or, even if tests do not indicate a significant delay, informed clinical opinion can be used to admit a child into the program. For children ages 3-5, criteria are similar but an additional requirement is the need for special education.



Outcomes

The National Early Intervention Longitudinal Study (NEILS) followed a large sample of children who received Early Intervention as infants and toddlers. The final report found that when they reached kindergarten, 42 percent of them performed as well as other children in reading and math and did not need special education.

There were also benefits for those who continued to need special education: five out of six families reported that their children were better off because of Early Intervention. A great majority of families reported positive family outcomes, including a greater understanding of their child's development, better support systems, and experience working with professionals and advocating for their child.²

How Pennsylvania's Early Intervention System is Supposed to Work

In Pennsylvania the Early Intervention programs for children from birth to three and three to five jointly administer Child Find, a process to identify, locate and refer children as early as possible. However, referral patterns indicate that the system for infants and toddlers depends heavily on health care providers to identify and refer children who are at risk of delay, while the system for preschoolers relies on a greater variety of social service and early childhood education providers.

Infant/Toddler Early Intervention

Pennsylvania has identified five factors that should automatically trigger screening, evaluation and either therapeutic services or continued monitoring of infants and toddlers with suspected developmental delays or disabilities. These are: (1) very low birth weight; (2) birth to a chemically-dependent mother; (3) having been abused or neglected; (4) an elevated presence of lead in the child's blood; and having been placed in the Neonatal Intensive Care Unit after birth. A child with any of these risk factors is eligible for evaluation if a delay is suspected.

Most often, children are referred to Early Intervention by a parent, caregiver, or health care provider as a result of routine screening or after a parent has expressed concern about the child's development. A significant number of referrals are also made by child protective agencies⁷ and an array of public health, early childhood education and social service agencies.

Once children are evaluated and found eligible, the Early Intervention system should move them toward receiving services. Typically, parents speak with a service coordinator from their county Early Intervention agency over the telephone. The service coordinator may visit their home to meet the child and explain the free and voluntary program. With parents' consent, a multidisciplinary evaluation (MDE) is conducted by specialists in fields such as physical and speech therapy. The evaluation takes place in the child's "natural environment," one in which the child is most comfortable,

Criteria That Trigger Screening and Evaluation for Developmental Delay in Pennsylvania

1. A child born with very low birth weight
2. A child born to a chemically-dependent mother
3. A finding of abuse or neglect
4. An elevated lead level in child's blood
5. A child who was placed in the Neonatal Intensive Care Unit after birth

with participation from the family. In the optimal situation, once the MDE determines the child is eligible, a team is assembled (including the service coordinator and members of the family) and the team draws up his or her Individualized Family Service Plan (IFSP) in the same session.

If the child has a delay, the team works to create an Individualized Family Service Plan (IFSP) specifying the outcomes, supports and services that will be provided. Once the plan is complete, services are supposed to begin within two weeks. In most cases therapists come to the family's home and work with parents, modeling how to work with the child. Best practices call for an IFSP that is flexible and dynamic, with room to change with the child's needs, and is revised at least once a year.

In other cases, children who are found to have a developmental delay or disability, or who are in a high risk category but who do not show a significant delay, are followed closely by staff of the Early Intervention program and their developmental progress is monitored over time. Children followed in this way can and do move in and out of Early Intervention depending on their needs and the family's preferences.

Preschool Early Intervention

The Preschool program serves children from age three to five.⁸ Although similar to the program for infants and toddlers, there is a significant difference: its goal is to prepare children for school through special education and other services. For this reason, the eligibility criteria are different: all children, regardless of their degree of delay or the nature of their impairments, must be "in need of special education and related services." Some young children are thus ineligible for services once they turn three because their delays do not require special education. For example, a child with a physical, but not cognitive disability might fall into this category. There are no national standards to define what constitutes the need for special education. In Pennsylvania the need for special education is determined by the Preschool Early Intervention agency in each county.

Identifying Children Who Can Benefit

Early Intervention is built on strong partnerships with health care providers, child care providers and social service agencies that reach into neighborhoods, especially where children are at higher than average risk of developmental delays. The stronger these partnerships, the more likely children will be referred because families are less likely to know that services are available.

Well-child visits to physicians play an important role in identifying young children with delays. Standards of pediatric care recommend developmental assessments at every visit to the doctor, ranging from every other month (for infants) to every year (for children age three and up). Across the state, these doctor visits account for most referrals for children under three. Medicaid requires primary health care providers to assess infants and toddlers at regular intervals for developmental progress or lags. The best practice is for the primary care provider to counsel the child's parent or caregiver and make a direct referral to Early Intervention, but not all health care providers follow this procedure. Some of this failure has been tied to weaknesses in the Medicaid and Child Health Insurance Program (CHIP) systems and is not unique to Pennsylvania.⁹ Recent reforms to the Medicaid payment structure may help close this gap, but much more can be done to improve the connections between children's primary health care providers and the Early Intervention system, which we discuss in detail in this report. Medicaid Managed Care insurers have the potential to leverage changes that could change outcomes for large numbers of Philadelphia children.

Typically, as children grow the presence of delays is more easily identified and parents are more likely to be familiar with developmental milestones. Children are more likely to spend time in group settings that facilitate comparisons with their peers. Thus, the number of children participating in early intervention shows a marked climb with each year of age. This increase is reflected in statewide participation rates: 7.6 percent of infants and toddlers received services in 2010-2011 compared with 10.6 percent of children ages three and four.¹⁰

Child care practitioners can play a critical role in helping parents understand their child's development and discuss suspected delays. For this reason, Pennsylvania has formally

expanded the role of early childhood education practitioners in screening children in recent years. The Office of Child Development and Early Learning (OCDEL) provides all early childhood education programs with a developmental screening tool, the Ages and Stages Questionnaire (ASQ), and training in its use.¹¹ Keystone STARS, the state's child care quality improvement system that reaches 49 percent of Philadelphia's regulated child care programs, provides professional education and technical assistance to help practitioners communicate with parents. Early childhood education programs rated STAR 2 through 4 (on a scale of 1 to 4) must complete a developmental assessment for each child enrolled and share the results with the child's parent or caregiver. However, only 16 percent of Philadelphia children who are enrolled in licensed early childhood programs are in programs that are rated STAR 2 and above.¹² Thus only a small share is likely to be screened while in child care.

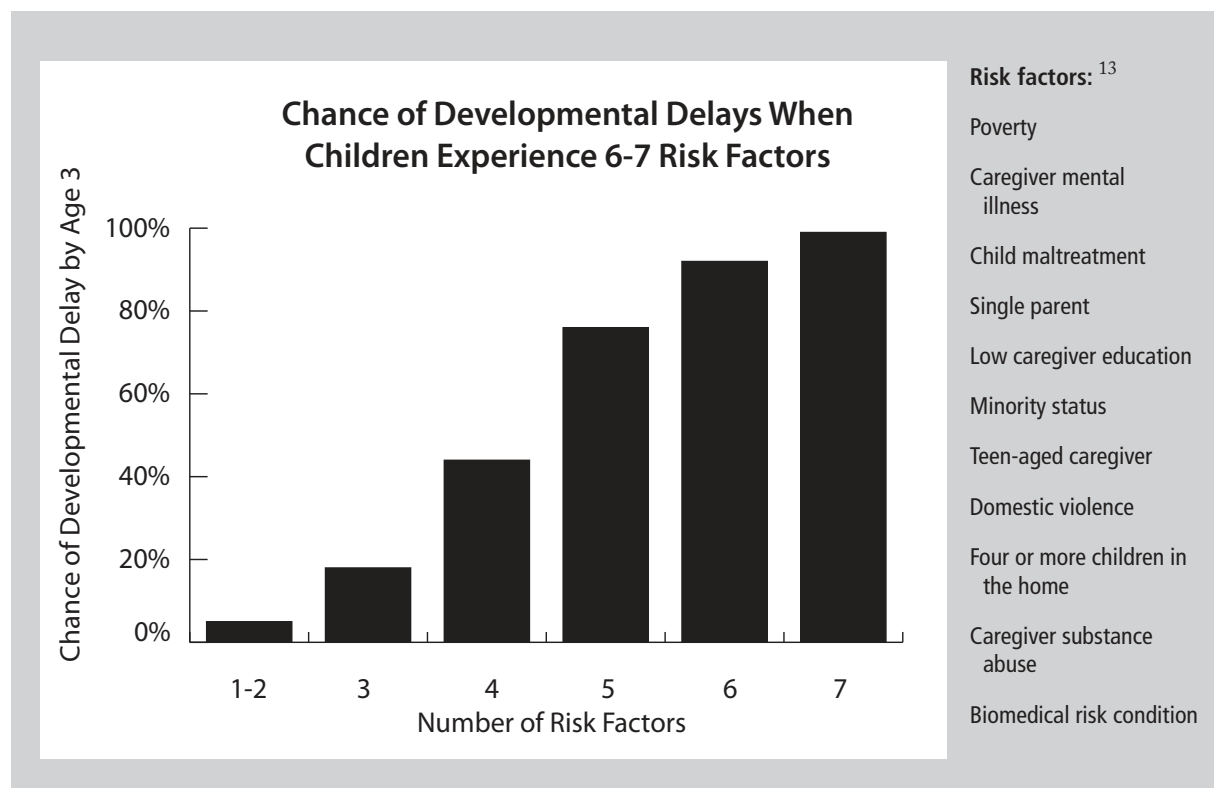


Figure 1: The more adversity a child faces, the greater the odds of a developmental delay. Risk factors have a cumulative impact on a child's cognitive, language or emotional development. a child who experiences multiple risk factors is more likely than not to experience a developmental delay which, if not treated early, could last into adulthood.

SOURCE: Barth, R.P., Scarborough, A., Lloyd, E.C., Losby, J., Casanueva, C., & Mann, T. (2008). Developmental Status and Early Intervention Service Needs of Maltreated Children. Washington, DC: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation.

Settings for Service

For infants and toddlers, federal law requires Early Intervention services be provided in the child’s “natural environment” and in Philadelphia virtually all services are currently delivered at home or in other “natural” settings. This phrase refers to any place the child spends time – with relatives, in child care, at the playground, or at home.

After the child’s third birthday, Early Intervention is most often provided in a classroom setting where segregating children with disabilities is strongly discouraged. In an “inclusive” setting, children are able to learn alongside their typically developing peers. Seven in ten preschoolers in Early Intervention currently learn in inclusive settings, but space in these programs is limited, especially for children with more severe physical or behavioral impairments.¹⁴ Pennsylvania requires publicly-funded quality early learning programs to serve a minimum number of children with disabilities or a minimum who are low-income, and doubled this requirement on January 1, 2013 to 10 percent.¹⁵

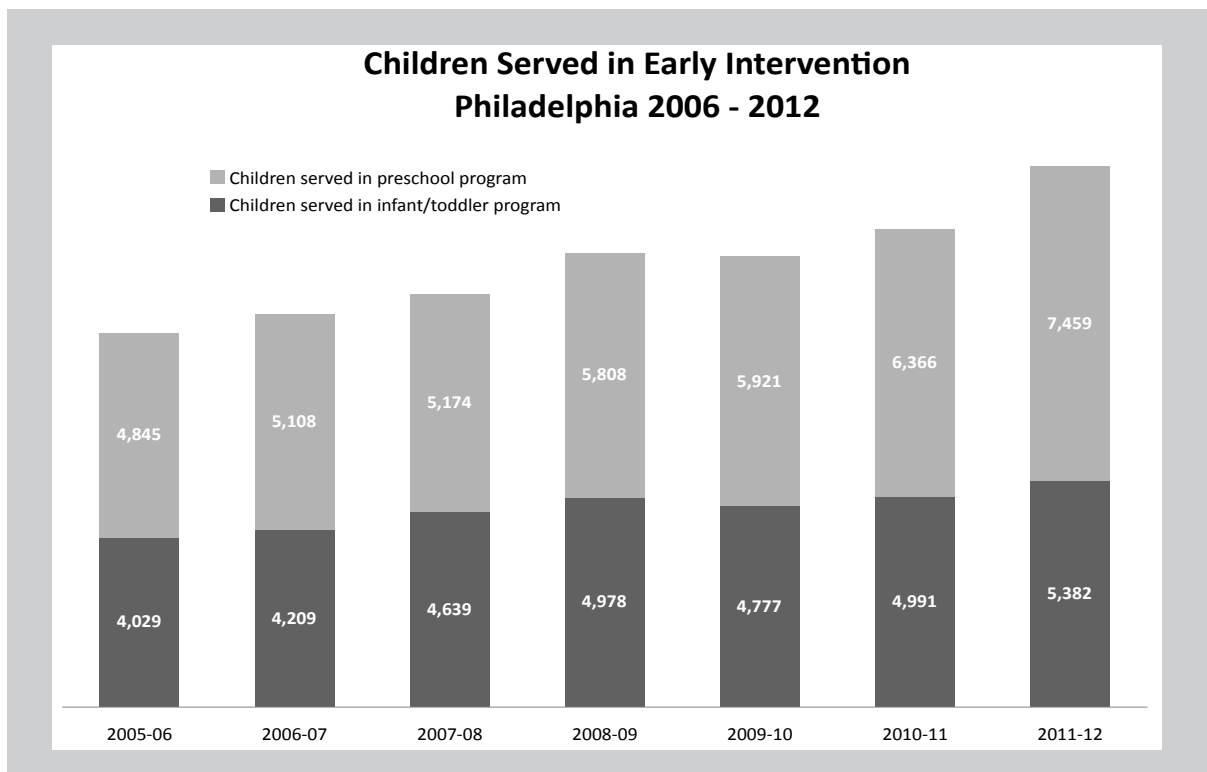


Figure 2: The number of children served in Philadelphia’s Preschool Early Intervention program has increased significantly, but the Infant/Toddler program has grown at a slower pace.

Early Intervention in Philadelphia: How it Actually Works

Participation in Early Intervention has expanded in Philadelphia, along with the rest of the state. Even so, many children in the city are not receiving Early Intervention services, are referred but never evaluated, or drop out of the system even though they could benefit from the services it offers.

Over the 2011-12 program year, Early Intervention served nearly 13,000 children in Philadelphia, as shown in Figure 2 on the facing page. One in eight children from birth to five received services at some point, up from one in twelve the previous year.¹⁶ Even so, Philadelphia's participation lags behind that of other cities in Pennsylvania, according to the most recent available data.

Considering the city's higher-than-average risk factors – its high rates of child poverty, lead exposure, children with low birth weight, and cases of abuse and neglect (see Table 1, below) – we should expect to see the state's highest rates of service.

For several years, Philadelphia has lagged behind other Pennsylvania cities in terms of its per capita participation in Early Intervention. In 2009-10, the state released municipal data indicating one in five children in Pittsburgh, Erie, and Harrisburg, and one in four in Reading, received Early Intervention.¹⁷ The following year, data continued to

Prevalence of Risk for Developmental Delay in Philadelphia¹⁸

Risk Factors	PA	Philadelphia
Poverty (0-5)	21%	35%
Very Low birth weight < 1500g	1.6%	2.5%
Stay in NICU	n.a.	2,171 children
Lead exposure, < 6 years old	0.75%	2.54%
Mother dropped out of high school	15.8%	24%
Abuse or neglect (0-4)	825 cases	199 cases
as a percentage	0.11%	0.20%

Table 1: A larger percentage of children in Philadelphia are exposed to risk factors for developmental delays than the statewide average.



The differences in rates of participation between cities mean that a child's developmental outcome may be determined in part by his or her place of residence.

show that most large cities had higher participation rates than Philadelphia. If Reading's, Pittsburgh's or Erie's rates were applied to Philadelphia, at least 3,000 and up to 7,000 additional children under the age of five would have received Early Intervention services here.

The chart below compares Philadelphia's rate of participation with other cities in which children are at greater-than-average risk of developmental delay.¹⁹ Philadelphia has the lowest rate. The chart shows variation in service patterns as well: in Pittsburgh, Lancaster and Harrisburg, many more preschool-age children participate in Early Intervention than infants and toddlers. In other cities this difference is less pronounced, and in a few cases, such as Erie and Bethlehem, the reverse is true. One factor may be the lack of statewide standard that defines "need for special education."

This suggests that the variation among Pennsylvania cities is tied more closely to local systems to identify and enroll children than to the actual level of need for Early Intervention in a given area.

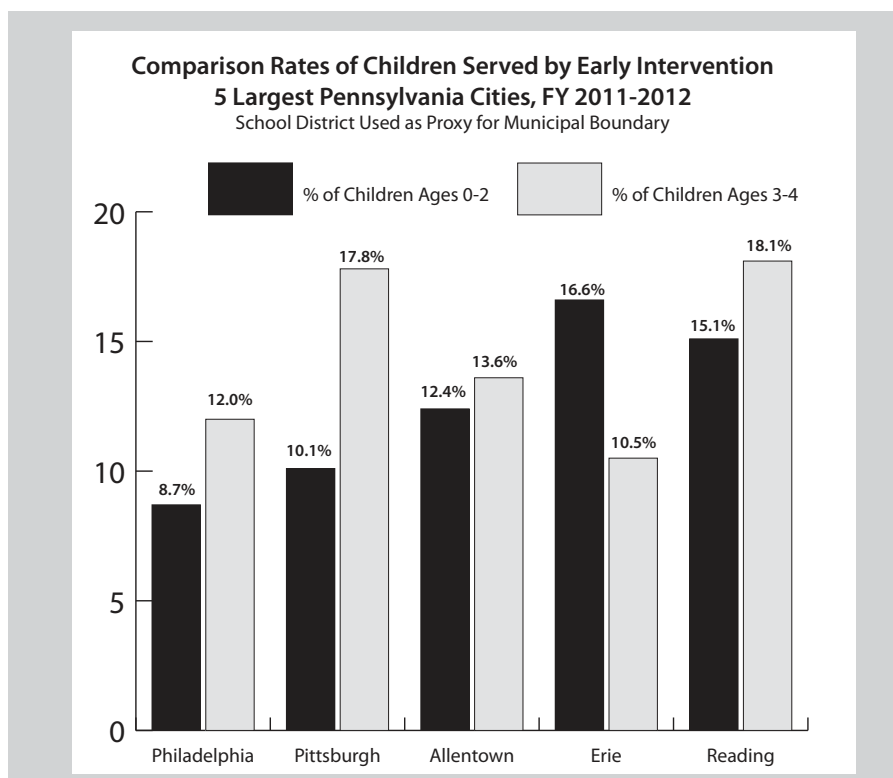


Figure 3: In the last year that comparative figures were available, Philadelphia's Early Intervention programs served a lower percentage of children than other cities, despite a child population with higher than average prevalence of risk.

Developmental Screening: Many Children in Philadelphia Never Make It to the First Step

Screening is the first step in obtaining services for children with developmental delays. However, the systems currently in place do not have sufficient capacity to reach all children in need, given the level of risk factors here. In order for all children to obtain the services they need, Philadelphia should move toward a system of universal screening, so that every child would have multiple opportunities to be screened at each stage of development.

Through Child Find – the process of locating, evaluating, and identifying children with delays or disabilities who may be in need of Early Intervention – developmental screening is conducted regularly at WIC offices, health centers, and other locations, and multilingual materials are targeted towards difficult-to-reach and underrepresented populations.

Even among children who do receive routine developmental screening from their health care providers, two out of every three children identified by physicians as needing follow-up do not make it to the critical evaluation step. Children's Hospital of Philadelphia (CHOP) researchers found that pediatricians made formal referrals less than half of the time when children failed a developmental screening, and ultimately only 11 percent of children in need received services.²⁰ The researchers found that standard follow-up methods such as handing parents a referral form or brochure are ineffective with low-income and poorly-educated parents. For some, spending a few minutes with the pediatrician may not be enough to understand that their child has a delay and what they can do to help him or her. Parents with low literacy skills are most challenged by this process.

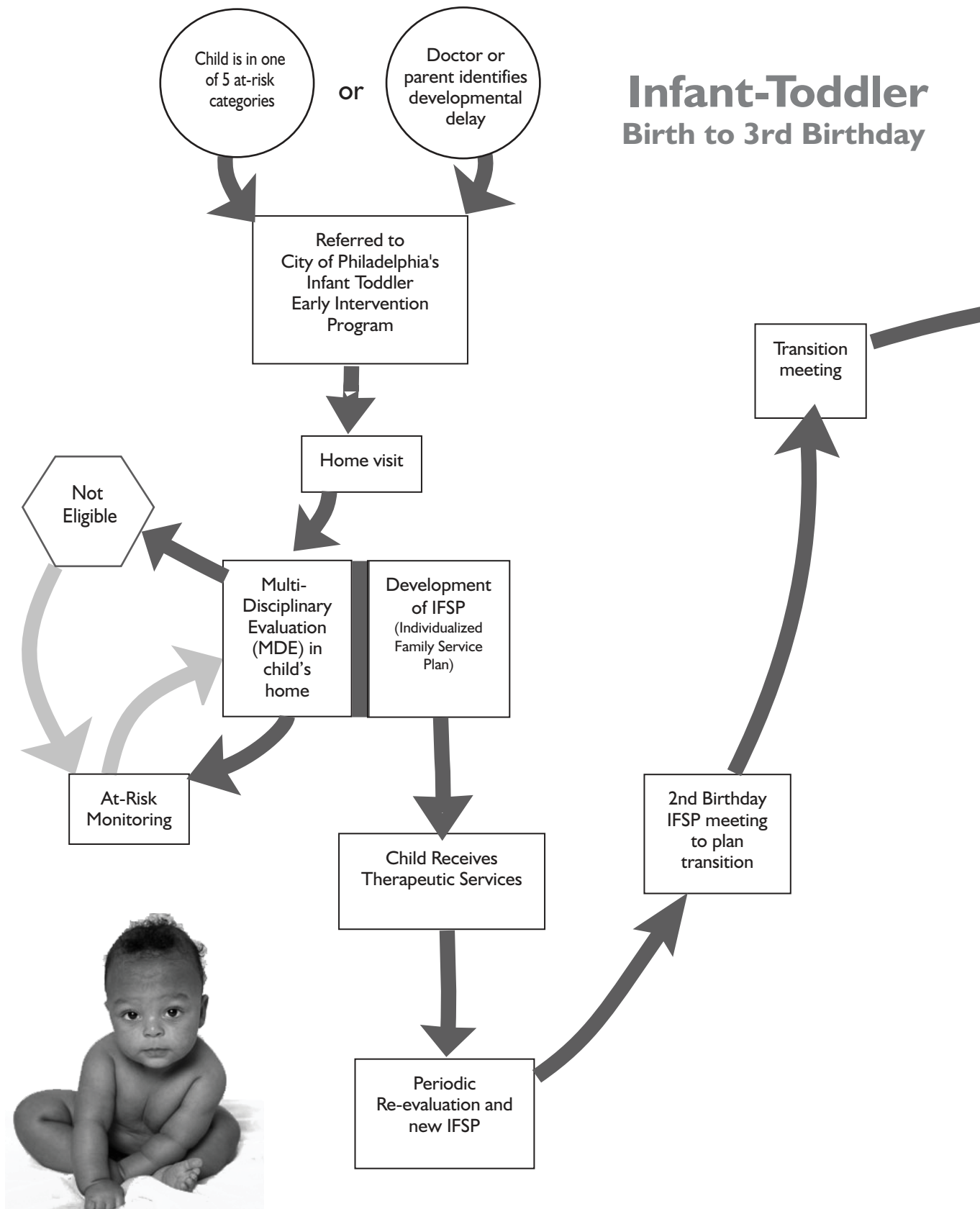
In addition, misunderstandings about Early Intervention abound. Some parents believe they are protecting their children from labels by keeping them out of Early Intervention. Helping parents overcome powerful stigmas associated with disabilities and special education, and helping them understand that Early Intervention can eliminate the need for special education, often requires a series of conversations that unfold over the course of several visits to the doctor. To follow up effectively, health care providers must be

" At first you're in a lot of denial. You think, 'she'll be OK.' Before my daughter turned one, the doctor suggested we take her to a specialist and also referred us to ChildLink."

– Denise, West Philadelphia

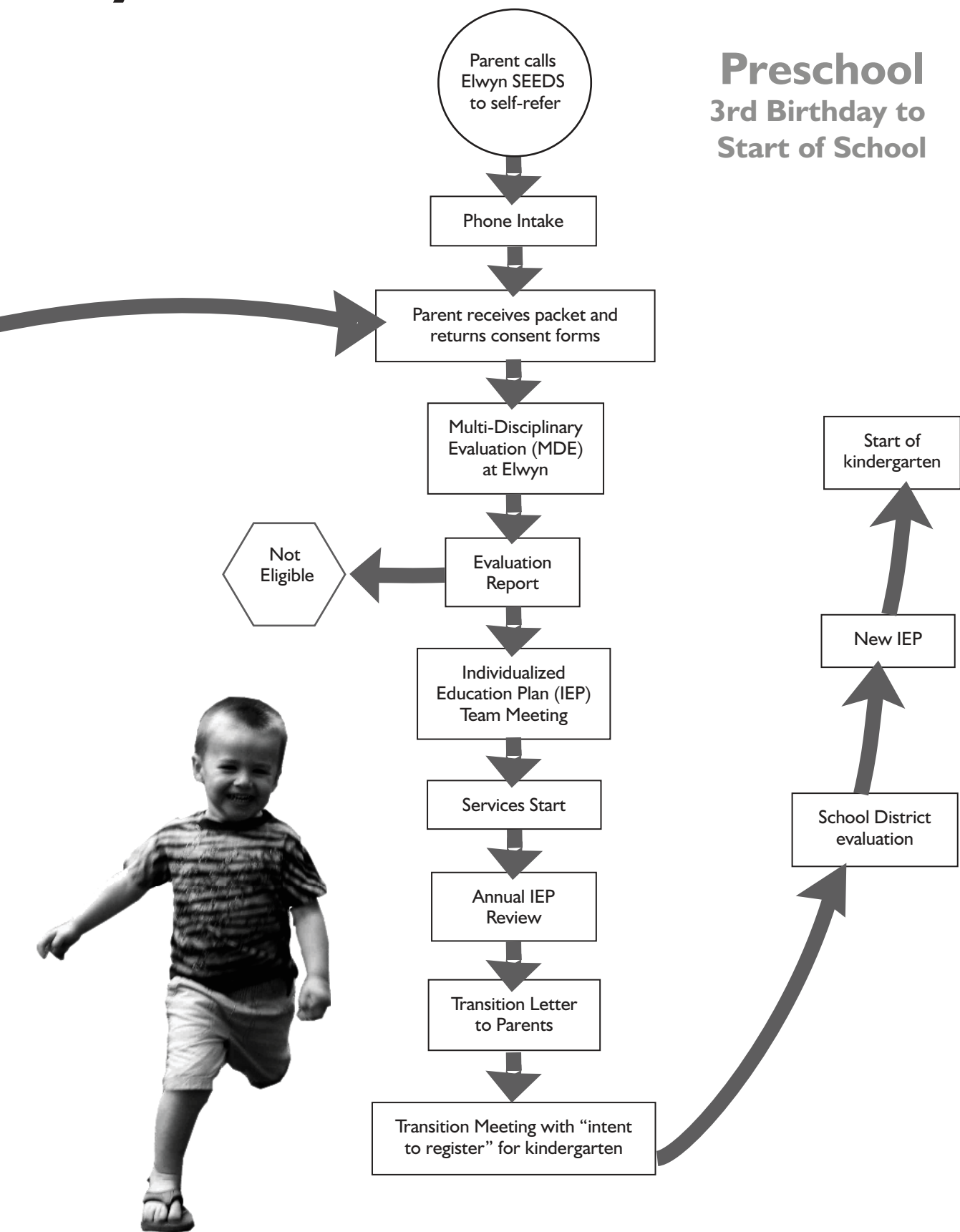
A Child's Path Through

Infant-Toddler Birth to 3rd Birthday



Early Intervention

Preschool
3rd Birthday to
Start of School



kept informed by Early Intervention agencies about the results of patient referrals. Better systems are evolving to do this, but they are not universally available to pediatricians.

For children over the age of two, the patterns of identification of developmental delays are different from those for infants and toddlers. In recent years in Philadelphia, the largest sources of referrals to Preschool Early Intervention (apart from children transitioning from the Infant/Toddler program) have been self-referrals from parents – though we have no way of knowing whether parents called after their child was screened by one of these other systems. Both Head Start and the City’s Department of Human Services (DHS) routinely screen all children in their care for developmental delays and account for significant numbers of referrals. Typically, few referrals for children three and over come from physicians or health and social service agencies. OCDEL anticipates that over time, other early childhood educators will provide a greater share of referrals.²¹



Despite Growth and Improved Operations, Too Many Children are Still Lost from the System

It is critical that Early Intervention systems identify children with developmental delays and disabilities as early as possible, while they can be treated most easily and effectively.

The good news is that for the youngest Philadelphians with special needs, indicators reveal improvements in recent years: the Infant/Toddler program's numbers are growing, it is providing more services to children under the age of one; it has achieved significantly shorter timelines for getting services started; and it is working aggressively to counter shortages in the supply of trained specialists.

Given advances in early diagnosis for many conditions related to developmental delays, and increasing numbers of children born into poverty in the city, we would expect the number of children served in Philadelphia to be high *and* increasing.

One indicator, the number of children with active IFSPs, increased significantly from 3.51 percent in FY 2010-11 to 4.59 percent in FY 2011-12.²² This increase is good news, and may be partly attributable to a public information campaign that ran public services announcements on TV. However, because similar increases occurred across the state, Philadelphia continued to lag behind the state average, despite having among the highest risk factors.²³

As we noted, action to continue to make sure pediatricians screen, follow through with referrals and communicate better with families could make the greatest contribution to bringing children in need into the system. But closing the evaluation gap matters too, as the system is losing 35 percent of children who are referred.

In the past Philadelphia's Infant/Toddler Early Intervention program had difficulty moving from referral to providing services within the 60-day timeframe established by federal guidelines. Only a few years ago, fewer than half the children in the program received timely services, and in 2010-11 it was two in three. But in a significant improvement last year, 93 percent received services in a timely manner.

Over the course of the year, nearly one thousand children with high levels of risk (see box on page 6) were monitored closely through the Infant/Toddler “at-risk tracking” program; these children were periodically re-evaluated and brought into the system if there were indications that they needed services.

Four in Nine Children Referred Received Services

As Figure 4 shows, in 2010-11 only 43 percent – four in nine – of infants and toddlers who were referred to Early Intervention ultimately received services. Only 65 percent of children referred to the program were evaluated. Two thirds of them were found eligible, and virtually all of the children found eligible moved on to receive services.²⁴ Some children were lost when parents declined services or were overwhelmed by wait times, paperwork and other logistical problems. Closing this gap by making sure more children who are referred are actually evaluated would be a significant gain for children from the most vulnerable families, who have had the most difficulty following up in the past.²⁵



Figure 4: The majority of children referred to Philadelphia’s Infant/Toddler Early Intervention program were either never evaluated or were found ineligible for services.

...And There is a Shortage of Specialists

Effective Early Intervention rests on the availability of high-quality trained professionals and specialists to deliver services. Philadelphia suffers from a shortage of these professionals, in particular speech therapists. The City's Infant/Toddler Early Intervention program contracts with over 40 service providers to match children with appropriate professionals. Despite focused efforts to improve this, the program struggles to find enough qualified therapists willing to provide home-based services at current pay rates. In order to address the shortage of specialists, the City's Department of Behavioral Health and Intellectual disAbilities has been working with area universities to increase the supply of therapists. It is hoped this effort will bear fruit in the future.



Best practice: Aggressive outreach and a grassroots network

Philadelphia could learn from the example of Allegheny County, whose Early Intervention programs are actively marketed and targeted where the need is greatest. The Allegheny County Alliance for Infants and Toddlers has an aggressive community outreach program to ensure that the large network of neighborhood-based family support centers, health and child care providers, libraries, shelters and domestic violence programs provide developmental screening and referrals. Much of the outreach is concentrated in Pittsburgh, which is considered higher risk than the surrounding areas in Allegheny County. The outreach shows: Pittsburgh serves a far greater percentage of children in Early Intervention than Philadelphia.²⁶ (see Fig. 3)

Allegheny County has a single point of entry for all publicly-funded early learning programs for children from three to five, including Head Start and Pre-K Counts. Parents who call this hotline for information are tracked in a data system; every inquiry is followed up on to make sure parents do not get lost as they try to navigate services for their children. Each caller is assigned an advocate who visits parents at home and helps them fill out the necessary applications. The advocate also explains developmental screening and Early Intervention, if appropriate. Calls for information to this hotline are not stigmatized as they might be to a service that is only for children with special needs.

Challenges in Meeting the Growing Demand for Preschool-Age Services

Most observers point to a cumbersome entrance procedure, difficulty communicating with a service coordinator, inconsistent monitoring of services and low rates of screening and referral as major problems for the Preschool Early Intervention program in Philadelphia.

Recent History

Elwyn SEEDS²⁷ has been Philadelphia's Preschool Early Intervention provider since 1998. For the most part, the organization evaluates children and coordinates the development of Individualized Education Plans (IEP), while subcontracting most direct services to 15 independent agencies.

From 2006-2010 the number of children Elwyn SEEDS served grew nearly 20 percent. There were indications that the agency was overwhelmed by the increasing demand by 2010 and was not providing evaluations or services to all clients in a timely manner. Parents reported disparate and inconsistent experiences with the agency, including numerous phone calls, visits and delays that left them discouraged and caused them to drop out at some point in the intake or transition process. Parents complained that during these service interruptions, which stretched from weeks to months in some cases, children were losing progress they had gained.²⁸

In the last year, Elwyn experienced another 10 percent increase over the previous program year. The agency increased the number of service coordinators, but continues to struggle to cope with the steep increase in demand.

Problems with Preschool Transition

Typically about two in five children, or about 1800 per year, who enroll in Preschool Early Intervention enter from the Infant/Toddler program.²⁹ Timeliness is one important factor in a successful transition, and although Elwyn has made rapid progress in the last two years, there is still room for

" We had a good experience with Early Intervention until it was time to transition. No one returned my repeated phone calls to get the transition started, schedule the evaluation and the IEP meeting. Each time I felt like I had to stalk them. Finally, my son started getting all the services, two and a half months after his third birthday. It seemed like they wanted you to quit!"

-- Diane, Lower Northeast

improvement.

Many families have reported experiencing disruptions in Early Intervention services as their child transitioned from the Infant/Toddler to the Preschool program. Some drop out during the transition process. This is in part because the system requires families to embark on a more cumbersome process than they went through with Infant/Toddler Early Intervention before they can be scheduled with a service provider.

Of children transitioning from Infant/Toddler to Preschool Early Intervention in FY 2009-10, only 44 percent had an IEP ready by their third birthdays, as federal guidelines require, and thus the majority were not able to receive therapeutic services as their Infant/Toddler services were scheduled to end. In contrast, nearly all other counties in the state reported that they provided timely services at or near 100 percent. However, by FY 2011-12 four out of five eligible children that Infant/Toddler Early Intervention referred to Elwyn received services by their third birthdays.³⁰

For some children, the delay was caused by the fact that Elwyn requires a new evaluation and IEP meeting even if the last one conducted by ChildLink was within the year,



Parents as Advocates

Philadelphia's Early Intervention system depends on a great degree of parental involvement to ensure that children receive high quality services consistently over time. This is especially true at moments of transition when children enter the system, move from Infant/Toddler to Preschool Early Intervention, and start kindergarten. It is true at other times as well. For example, parents must advocate for timely replacements when turnover occurs among service coordinators and therapists, or when staff do not return phone calls on a timely

basis. They must advocate for their children to get into inclusive classrooms. They must often transport their children to therapies during the middle of the day. Expectations such as these are difficult for the majority of working parents to manage. They are especially challenging for parents with low literacy skills, limited English proficiency, and those who do not see themselves as advocates. Many parents find peer support groups extremely helpful in learning how to work with the Early Intervention system. (See page 32 for more information.)



Promising Practices

City of Philadelphia Initiatives

In recent years the City of Philadelphia has taken important steps to increase the number of children screened for developmental delays, targeting those most at risk.

Based on results from the MOM program, a five-year study (2001-2006) conducted by Children's Hospital of Philadelphia that provided home visiting and support services for new mothers, the City has begun a similar pilot program in North Philadelphia, which it plans to scale up. The original MOM trial resulted in twice as many children enrolling in Head Start as in the control group (46 *vs.* 23 percent) and nearly three times as many participating in Early Intervention up to age three – 18.8 percent *vs.* 6.3 percent.³¹

Recognizing that trauma, exposure to violence, and above average rates of exposure to substance abuse place homeless children at high risk of developmental delays, the City's Office of Supportive Housing screens all children in homeless shelters and offers follow-up services to those found to have delays.

The School District of Philadelphia

By virtue of the number of children it serves and the high quality of assistance it provides, the School District of Philadelphia (SDP) has played an essential role in identifying preschool children with special needs and helping their families secure services. With dozens of community-based partners, the School District enrolls 8,844 children in quality preschool programs, including 6,267 in

its Head Start program. Every child in these early learning programs is routinely screened for developmental delays. When the screening indicates a delay, an agreement with Elwyn SEEDS enables Head Start children to be evaluated for Early Intervention in their regular classrooms, rather than requiring parents to schedule appointments at Elwyn's office in West Philadelphia. This also facilitates participation of the child's teacher.

The School District employs ten special needs coordinators to support approximately 1,000 children who receive Early Intervention through Head Start and its other pre-k programs. The coordinators are experienced special education teachers who help guide children and families through the Early Intervention system and advocate for them as necessary. Coordinators address interruptions in service and provide follow-up for children whose parents opt not to enroll them in Early Intervention. Their close working relationships with preschool teachers help them gain parents' trust and support the parents in becoming advocates for their children. More research is needed to know conclusively whether this advocacy results in significantly higher participation in Early Intervention.

While the School District provides good care to families of preschool students with developmental delays, its ability to continue this service is in jeopardy. Through a series of budget cuts enacted since 2008, SDP has lost ten percent of its pre-k capacity and continues to face serious financial pressure. Nevertheless, it must find a way to preserve and expand its capacity to identify children with developmental delays and to help their families obtain services.

which is not required by law. Even when this was done before their third birthday, some children experienced long waits for therapists from the Preschool program. Children whose services lapse, and children who take time to adjust to a new therapist, may lose the gains made in therapy during this period. These problems would have been alleviated if the transition process facilitated continuing with their Infant/Toddler service providers until the new Preschool programming was set up. Although such a continuation is OCDEL's official policy, in practice many parents in Philadelphia found they had to make a formal complaint.

Barriers Remain for Preschool Children with Special Needs

For children who are referred to Early Intervention as preschoolers, barriers remain to entering the system. A look at 4,485 referrals received by Elwyn in FY 2011-12 shows that one in three children were not evaluated. Of those whose parents persevered until their children were evaluated, 82 percent were found eligible. However, some of them dropped out before the IEP was prepared and still others did not receive services. Ultimately, only one in three children who were referred for help actually received therapeutic services.³²

A Shortage of Inclusive Classrooms

In contrast to home-based services for infants and toddlers, Preschool Early Intervention is usually provided in a classroom setting. Participation in an inclusive early childhood education program is an important complement to therapies that specialists provide for several hours each week. But access to early childhood education depends on a sufficient number of inclusive classrooms in which children with special needs can learn alongside of typically developing peers. Now 70 percent of all Philadelphia three to five year-olds in Early Intervention receive services in inclusive environments.³³ Although Philadelphia was ahead of the state average of percentage of children served in inclusive classrooms, other counties have moved ahead more quickly.³⁴ There are long waiting lists for inclusive preschool classrooms in Philadelphia. Indeed, some children are already enrolled in

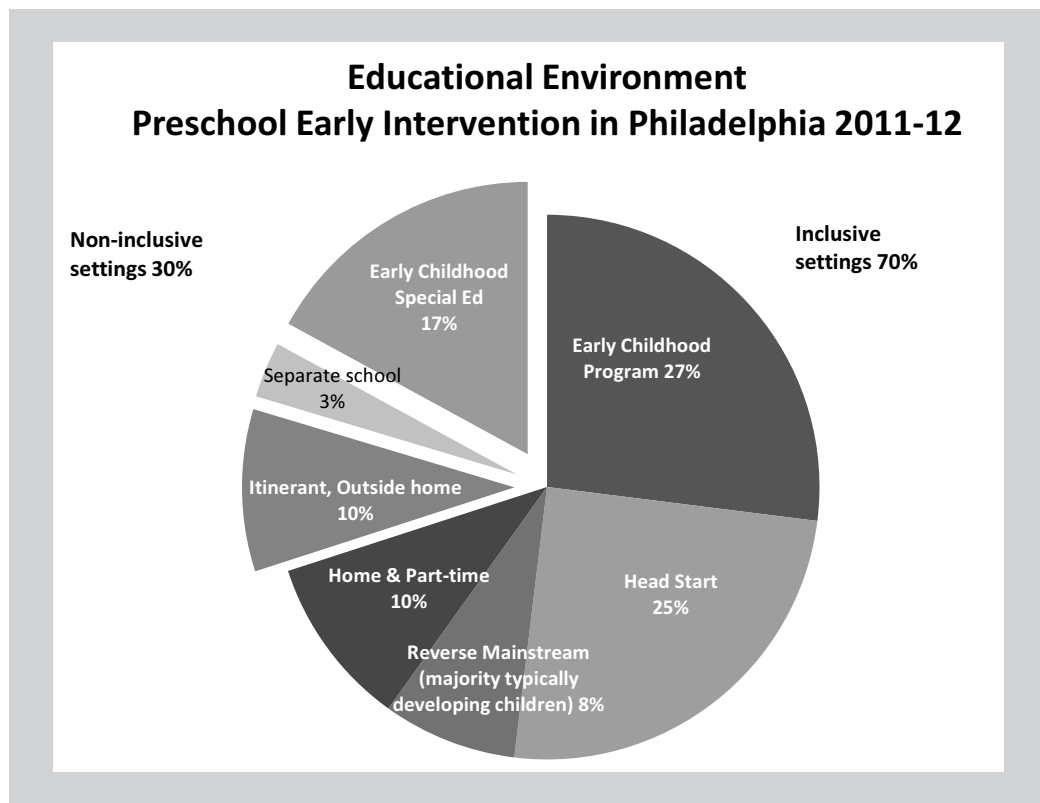


Figure 5: More than half of children in preschool Early Intervention were served in early childhood education programs, and a full 70 percent were served in inclusive classrooms.

kindergarten by the time space opens up.

The remaining 30 percent of children who receive Early Intervention are served in settings considered non-inclusive: special learning programs that a child may attend for a few hours per day or week; separate schools; or itinerant services provided outside the home. For example, Elwyn provides a number of special classroom programs for autistic children throughout the city.³⁵ Because of the limitations of these classrooms, children who participate in them miss out on the opportunity to learn alongside of typically-developing peers, while their parents are challenged to find settings to care for them during the remainder of the week.

In addition to serving children enrolled in Early Intervention, inclusive, high quality early learning programs – where teachers and staff are sensitive to children with special needs and have greater knowledge about child development – are superior settings for all children at risk of delays, including

the many children with milder delays who are ineligible for Early Intervention, as well as those who are eligible but not enrolled.

Transition to Kindergarten

The transition to kindergarten can be difficult for families of children with developmental delays. The School District of Philadelphia requires yet another evaluation, which slows the process down. For example, by late August, 2011, 40 percent of children transitioning from Preschool Early Intervention to kindergarten had not yet been evaluated by the School District.

Parents often do not receive timely information about options that will be available to their children in kindergarten; sometimes they receive information only after the school year begins. Many parents opt to keep their children in Early Intervention for an additional year, in part due to a lack of information or trust in what the public education system can offer them.

Local stakeholders – OCDEL, the School District and the City – should have a strong interest in streamlining the transition from Pre-school Early Intervention to the School District.

"When it was time to transition to the School District, we got a huge runaround. It seemed like they were trying to weed kids out. We filled out all the forms, but there was no address. You had to hand-deliver them or fax them in. Who has a fax machine? And everything seemed so last-minute."

— Jean, Port Richmond



Recommendations

PCCY offers these recommendations to improve the Early Intervention system in Philadelphia so that it serves all eligible children with developmental disabilities and delays, improves school readiness and reduces the need for special education. Two major recommendations would have the highest impact on outcomes for Philadelphia children:

- End the bifurcated system which is at the root of several of the barriers that prevent many of our most vulnerable families from accessing Early Intervention services. Unify Infant/Toddler and Preschool programs under a single entity to improve operations, bridge the programs' different eligibility requirements and goals, and streamline the transition process at age three, preventing interruptions in services that are too common today.
- Build a stronger high quality early learning system that can help every child develop to her or his potential and be ready for school. This means funding Pre-K Counts, Keystone STARS and other early childhood education programs to complement Early Intervention therapies and, in some cases, prevent the occurrence of developmental delays. Significantly increase the level of inclusive, high quality seats so that every child in Early Intervention – as well as children with milder delays -- has the option to benefit from these programs, regardless of family income. OCDEL should invest in the development of a high-quality program for high-risk infants and toddlers, the counterpart to Pre-K Counts, to focus on school readiness and preventing the need for special education.

Because these are large, systemic changes that will take time to implement, the following should be done immediately:

The City and School District of Philadelphia together:

- Establish goals and specific targets for increasing incrementally the number of at-risk children who are screened for developmental delay.
- Implement a campaign to promote the importance of school readiness through mass media and grassroots efforts. Objectives include educating parents and caregivers about developmental milestones from birth to five, reducing the stigma associated with developmental delays, and spreading the word about Early Intervention as a preventive program with positive outcomes.

The City:

- Mobilize its network of social service providers and community-based organizations to increase the reach of Child Find into the community and find new ways of targeting underserved populations and neighborhoods of highest risk, including immigrants and the poorest families.

Health providers and health systems:

- Work together with Early Intervention to ensure that every child who fails a developmental screening is referred and evaluated,
- Counsel parents and followed up appropriately;

- Work with Early Intervention providers to create an efficient feedback loop so that the child's primary care provider is kept informed.

Medicaid managed care plans:

- Hold primary care providers accountable for conducting all required screens and following up with referrals and parent counseling.

OCDEL:

- Ensure that counties serve all families equitably by working with them to remove existing financial, systemic, linguistic and cultural barriers to access. This includes additional reimbursement to programs that currently shoulder costs for foreign language translation and interpretation, for both Child Find and service delivery.
- Work with Elwyn to adopt goals to quickly move toward serving all children in inclusive settings. Implementation of this goal will require developing closer working relationships with and providing more flexible supports to a greater number of quality preschool and childcare programs;
- Continue to monitor coordination between Elwyn and the Infant/Toddler program to improve the transition experience for children and their families and to eliminate gaps in service.
- Continue to monitor the intake and service coordination processes at Elwyn to improve the quality and accessibility of those services, especially for more vulnerable families.

The School District and OCDEL:

- Work together to improve children's and families' experiences in the transition from Preschool Early Intervention to kindergarten.
- Hold transition meetings beginning in the Fall of the year prior to Kindergarten, and evaluate children early enough in the year so that parents know whether their child will have an IEP in Kindergarten, and if so, what services will be provided.
- Provide parents with more information about the District's Kindergarten options (and beyond) suitable to their child's special needs before Kindergarten registration begins.

The School District of Philadelphia:

- Use the child's IEP from Elwyn SEEDS for Kindergarten, if the School District cannot evaluate and complete its own IEP before the school year begins, so that no child begins school without services and every child who needs special education is able to start school with their peers.
- Continue the practice of providing coordination and advocacy for children in SDP-sponsored early childhood programs who need and are enrolled in Early Intervention.

Endnotes

1. James Harvey, *Invest Now or Pay More Later: Early Childhood Education Promises Savings to Pennsylvania School Districts* (Pennsylvania Build Initiative, 2006).
2. Hebbeler, Kathleen, Spiker, Donna and Bailey, Don, *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, 4-28, <http://www.sri.com/neils/reports.html>.
3. The Individuals with Disabilities Education Act (IDEA) provides the legal authority for early intervention and special education services for children from birth to age 21. Part B outlines services for children ages three to 21. Part C outlines services for children from birth to age three. Pennsylvania's law is Act 212 of 1990, the Early Intervention Systems Act. States may adopt their own definitions of eligibility, but infants and toddlers must receive services within 60 days and preschool children must receive them within 90 days according to federal guidelines.
4. The National Early Childhood Technical Assistance Center (NECTAC), *The Importance of Early Intervention for Infants and Toddlers with Disabilities and their Families*. The basis for this was a definition similar to what is used in Pennsylvania.
5. Coleen A. Boyle et al., "Trends in the Prevalence of Developmental Disabilities in US Children, 1997-2008," *Pediatrics* 127, no. 6 (June 1, 2011): 1034-1042, doi:10.1542/peds.2010-2989. See also L. Sices and C. Fund, *Developmental Screening in Primary Care: The Effectiveness of Current Practice and Recommendations for Improvement* (Commonwealth Fund, 2007), and Kavanaugh J, Gerdes M, Sell S, et al., *SERIES: An Integrated Approach to Supporting Child Development*, The Children's Hospital of Philadelphia Research Institute, Summer 2012. http://www.policylab.us/images/pdf/policylab_e2a_summer2012_series.pdf
6. The five major developmental areas, or domains, are cognitive, adaptive, physical, communication and social/emotional. A delay based on the child's age in months, e.g. a 24 month old with a 25 percent delay would be at the developmental level of an 18-month old. Qualifying health conditions include prematurity; genetic syndromes with known associations of delays; serious vision, hearing or speech problems; cerebral palsy; autism; and Down syndrome, among others. Under IDEA states may choose to expand eligibility to include risk factors.
7. A 2004 federal law requires that these children be referred for early intervention screening or evaluation, but not that they receive treatment, since early intervention is a voluntary program.
8. Technically the preschool program serves children from three until whenever they begin school, and parents have the option to extend Early Intervention for an additional year and delay entrance to kindergarten. There are usually as many five-year-olds in the program as four-year-olds.
9. Kenney, Genevieve M. and Pelletier, Jennifer E., *Improving the Lives of Young Children: The Role of Developmental Screenings in Medicaid and CHIP* (Urban Institute, December 2010).
10. Pennsylvania Office of Child Development and Early Learning (OCDEL) "Program Reach & Risk Assessment: 2010-2011 Report - updated July 2012," http://www.pakeys.org/pages/get.aspx?page=EarlyLearning_Reach.
11. OCDEL accepts other screening tools, but recommends and supports use of the Ages and Stages Questionnaire (ASQ) and Ages and Stages Social-Emotional (ASQ-SE), a generally accepted screening tool with high accuracy and reliability. Ibid.
12. Pennsylvania Office of Child Development and Early Learning (OCDEL) "Program Reach & Risk Assessment: 2010-2011 Report - updated July 2012," http://www.pakeys.org/pages/get.aspx?page=EarlyLearning_Reach. Keystone STAR ratings rely on research-based criteria for evaluating quality. These include staff qualifications and environmental factors.
13. Not all these risk factors for delay are criteria for high-risk tracking in Pennsylvania.
14. A full discussion of inclusive classrooms is beyond the scope of this report.
15. As part of OCDEL's Rising Stars initiative.
16. Comparing FY 2011-12 and 2010-11. Source: OCDEL, e-mail correspondence. September 7, 2012.

17. Based on OCDEL's Reach and Risk Report for FY 2009-2010.
18. Sources for Table 1: Poverty: U.S. Census American Community Survey 2008-10. Very low birth weight and admitted to NICU: <http://www.phila.gov/health/Commissioner/VitalStatistics.html>
Lead: PA Department of Health, Lead Poisoning Prevention and Control, Pennsylvania Childhood Lead Surveillance Program 2010 Annual Report http://pa.gov/portal/server.pt/community/lead_poisoning_prevention_control/14175
Mother less than 12 years education: KidsCount 2009
Substantiated abuse or neglect in children 0-4. KidsCount 2010
19. OCDEL's Reach and Risk Report from 2011-12. OCDEL no longer provides figures by municipality, so school districts have been used to approximate the cities' area.
20. Kavanaugh J, Gerdes M, Sell S, et al., *SERIES: An Integrated Approach to Supporting Child Development*, The Children's Hospital of Philadelphia Research Institute, Summer 2012, http://www.policylab.us/images/pdf/policylab_e2a_summer2012_series.pdf. see also Manuel E. Jimenez et al., "Barriers to Evaluation for Early Intervention Services: Parent and Early Intervention Employee Perspectives," *Academic Pediatrics* 12, no. 6 (November 2012): 551-557, doi:10.1016/j.acap.2012.08.006.
21. We do not know how many parents call as a result of a conversation with a child care provider. Referral figures exclude children coming from infant/toddler transition.
22. This measurement compares children with active IFSPs on a single date, December 1, 2011, so it is lower than the aggregate number or percent served over the course of the entire year.
23. OCDEL Reach and Risk Report, 2010-2011 (revised February, 2012).
24. OCDEL, correspondence Sept. 2011.
25. According to preliminary data from OCDEL received in September 2012, Philadelphia has made progress in closing the gap between the number of children referred and the number who eventually receive services. Final data were not yet available as of this writing.
26. OCDEL provided data by municipality in FY 2009-10 and by school district in 2010-11, so exact comparisons are not possible. However, these data indicate that Pittsburgh's rates of service were at least 50 percent higher than Philadelphia's in 2010-11 (12.3 vs. 8.4 percent) and twice as high in 2009-10 (20.0 vs. 8.3 percent).
27. SEEDS stands for Special Education for Early Developmental Success.
28. As a result of a 2010 legal complaint, OCDEL has worked closely with Elwyn to improve the operational problems that were causing these delays. The agency can now track children through its system and monitor the services they receive.
29. OCDEL correspondence September 7, 2012.
30. FY 2010 also showed improvement over the 44 percent measure in 2009-2010. Source: Penn Data for FY 2010 and 2011; OCDEL correspondence September 7, 2012 for FY 2012.
31. "The MOM Program Shown to Have Positive Effects on Children at Age 5 - Grant Results Reports - RWJF," *Robert Wood Johnson Foundation*, accessed June 21, 2011, <http://www.rwjf.org/reports/grr/058418.htm>.
32. OCDEL correspondence September 7, 2012.
33. Also considered inclusive environments are early childhood programs designed primarily for children with disabilities but where a majority of children are developing typically, called "reverse mainstream." A full discussion of inclusive classrooms is beyond the scope of this report.
34. The statewide average for FY 2011-12 was not yet available when this report was issued. In 2010-11 Philadelphia lagged behind the statewide average of 70 percent.
35. This is a special challenge in Philadelphia, where the share of children with autism in preschool early intervention is 15.3 percent, almost twice the statewide average of 8.7 percent.

Glossary

ASQ: The Ages and Stages Questionnaire, to identify children with developmental delays.

Child Find: Established as part of IDEA, Child Find is the process of locating, evaluating, and identifying children with delays or disabilities who may be in need of Early Intervention.

ChildLink: Program that is contracted by the Philadelphia Department of Behavioral Health and Intellectual DisAbilities Services to provide service coordination for Infant/Toddler Early Intervention.

Elwyn: A non-profit agency that is contracted by the state to provide Preschool Early Intervention in Philadelphia. Funded jointly by federal and state government.

IDEA: Individuals with Disabilities Education Act.

IDEA Part C: early intervention program for children from birth to their third birthday

IDEA Part B: early intervention program for children ages three to five (or beginning of school)

Inclusive environment: An environment supported by policies, practices and values that encourage participation of children with disabilities in activities along with typically developing children.

Individualized Education Plan (IEP): For children from three to five, a written plan detailing the child's strengths and needs, developmental and educational goals for the child, services to be provided and the settings where the services will occur.

Individualized Family Service Plan (IFSP): For children from birth to three, a written plan detailing the child's strengths and needs, family concerns, developmental goals for the child, services to be provided and the settings where the services will occur.

Keystone STARS: Pennsylvania's continuous quality improvement program for early care and education. It features a rating system from 1 to 4 stars, with 4 being the highest quality.

Least Restrictive Environment: Federal law requires services to be provided in places where any typically developing (non-disabled) child would be or would interact with family and peers.

Multidisciplinary Evaluation (MDE): The individualized evaluation process used to determine the strengths and needs of the child and family, and eligibility for early intervention services.

Natural Environment: Federal law requires that services for children up to age three be provided in the environment that fosters growth and development within the context of the family's daily routines and activities.

OCDEL, Pennsylvania's Office of Child Development and Early Learning, administers programs funded by the Department of Education and Department of Public Welfare, and has aligned many program standards across both agencies.

Pre-K Counts: Pennsylvania's high quality early childhood education program serving three- and four-year-olds at risk of school failure. Evidence shows a dramatic reduction in need for special education for children enrolled.

Significant Developmental Delay: In Pennsylvania, measured as at least 1.5 standard deviations below the norm or at least 25 percent behind other children of the same age (measured in months, for example, a 32-month old functioning at the level typical of a 24-month old is 25 percent delayed) in one or more areas: cognitive, communication, physical, social/emotional or adaptive.



Early Intervention Resources in Philadelphia

Elwyn SEEDS Intake and Evaluation 215-222-8054

<http://www.elwyn.org/program/seeds>

Philadelphia Infant Toddler Early Intervention Intake 215-685-4646

A Family Guide to Inclusive Early Learning in Pennsylvania. An 86-page guide from Education Law Center. November 2012.

<http://www.elc-pa.org/FamilyGuidetoEarlyLearningFinal.Nov.2012.pdf>

Health Intervention Program for Families (HIP) provides hands-on support to families who are raising children with special health care needs. Tel. 215-685-5225

<http://www.phila.gov/health/mcfh/hipfamilies.html>

Parent to Parent (P2P) provides one-to-one peer support for parents and family members of children and adults with special needs. Philadelphia office 267-546-9084

<http://www.parenttoparent.org>

Parent Partnership Program offers peer support by and for parents and caregivers of children served by Elwyn SEEDS. Monday - Friday, 10 A.M. - 2 P.M. 215-921-7169

Philadelphia Interagency Coordinating Council (PICC) brings together local families, service providers and agency representatives to share information, work together, and ensure the availability of quality early intervention services. 215-731-2464.

<http://www.philadelphiaicc.org/index.html>

Transition to Kindergarten: A Planning Guide for Parents. A 23-page guide from Elwyn and the School District of Philadelphia with information families need to know during the year before Kindergarten.

<http://www.elwyn.org/images/uploads/trans%20guide%202011%20FINAL%20FINAL%20FINAL.pdf>

OCDEL Bureau of Early Intervention's home page lists numerous resources, including guides for parents (many also available in Spanish) and service providers. http://www.portal.state.pa.us/portal/server.pt/community/early_intervention/8710

Public Citizens for Children and Youth (PCCY) serves as the leading child advocacy organization working to improve the lives and life chances of children in the region.

Through thoughtful and informed advocacy, community education, targeted service projects and budget analysis, PCCY watches out and speaks out for children and families. PCCY undertakes specific and focused projects in areas affecting the healthy growth and development of children, including child care, public education, child health, juvenile justice and child welfare.

Founded in 1980 as Philadelphia Citizens for Children and Youth, our name was changed in 2007 to better reflect our expanded work in the counties surrounding Philadelphia. PCCY remains a committed advocate and an independent watchdog for the well-being of all our children.

