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Using the Portal of Early Intervention for Healthy Development

The Philadelphia Case Study

RAYMOND'S STORY

Born nearly 2 months premature, Raymond weighed less than 3 pounds at birth. His mother's pregnancy had been complicated by her use of drugs, such as heroin, cocaine, and marijuana, as well as her ongoing methadone habit. Raymond remained in the neonatal intensive care unit (NICU) for more than a month as he went through withdrawal from opiates, received a transfusion for anemia of prematurity and phototherapy for jaundice, and experienced problems with feeding. Raymond also suffered from retinopathy of prematurity, which placed his vision at risk.

Raymond was discharged when he was a little more than 1 month old to his mother's care. The discharge plan included a referral to a pediatric ophthalmologist for eye surgery to correct the retinopathy and referral to the hospital's NICU follow-up program in 2 weeks to monitor his growth and the other distinctive health and developmental needs confronting this medically complex infant. When Raymond's mother repeatedly failed to take him to the eye doctor, the child protective services (CPS) hotline was notified because failure to address the retinopathy could result in blindness. Less than 3 weeks after discharge from the NICU, Raymond was removed from his mother's care and placed in foster care with the John Smith and James Conner family.

The foster parents were informed of Raymond's need to be seen by the eye doctor, and Raymond received laser surgery to treat the retinopathy of prematurity. After 5 months in their home, Raymond's foster parents were

concerned about his slow development, limited eye contact, and his tiny size. On their own initiative, they located the Starting Young (SY) program, a pediatric, interdisciplinary diagnostic and referral service exclusively for infants and toddlers who are involved with the child welfare system.

When evaluated by the SY team at 7 months of age, Raymond presented as a happy and active infant. Raymond's birth mother was invited to the evaluation, but she did not attend. During the evaluation, it was noted that Raymond exhibited amblyopia (sometimes called "lazy eye") in one eye. The foster parents reported that Raymond's feeding at home was going well.

The assessment of Raymond's cognitive, speech-language, and gross-motor development indicated significant delays in each of these domains, even when his prematurity was taken into account. The team recommended early intervention (EI) services (under Part C of the Individuals with Disabilities Education Act [IDEA] of 1997 [PL 105-17]) to address delayed early communication and gross motor skills. Due to his language delay, he was referred to a pediatric audiologist for a hearing evaluation.

The SY team also addressed the foster parents' concern about Raymond's tendency to avert his gaze and his limited eye contact. They informed the foster parents that gaze aversion can be a normal means of self-regulation for infants, and that Raymond tended to turn his eyes away when he needed a break from social interactions. The team also explained how Raymond's limited eye contact was a function of his "lazy eye," which made it difficult for him to focus directly on others. The foster parents were reassured by these explanations.

The pediatric assessment indicated that although Raymond's growth was appropriate when compared with the national norms for babies with very low birth weights, it still was on the low side and required monitoring by his pediatrician. Recommendations for hepatitis B screening and HIV testing were made due to maternal risk factors. It was also recommended that Raymond return to the ophthalmologist for evaluation of his amblyopia. The evaluation team encouraged a reevaluation with the SY clinic in 6 months to continue to monitor Raymond's health and development.

The foster parents followed through on many of the recommendations from the first evaluation. Raymond underwent corrective surgery for his amblyopia; he had his hearing evaluated, which indicated a mild hearing disability; and he took hepatitis B and HIV tests, which were negative. Raymond also began receiving EI services from a physical therapist to address his motor development and from a teacher who focused on communication skills.

Raymond returned with the foster parents for a reevaluation with the SY program when he was nearly 17 months old. Once again, his mother was invited to the session, agreed to attend, but did not show up. Throughout the evaluation, Raymond smiled and maintained good eye contact with the evaluators. He was attentive and turned his head toward speakers' voices. The

reevaluation indicated that Raymond excelled at verbal tasks. He performed at his age level on a variety of language-based measures, in contrast to his performance 10 months previously when he was found to have a 50% delay in communication skills. Raymond's gross motor skills also had improved significantly and currently were at age level.

Despite these excellent advances, Raymond had significant difficulty with both fine and visual motor skills, which required use of his hands, as well as eye-hand coordination. The SY team recommended that Raymond receive an evaluation by a pediatric occupational therapist through EI services and receive intervention, if warranted, to improve his ability with fine and visual motor activities. Reevaluation with the SY team was recommended in 6 months to continue to monitor his development.

Raymond returned for a reevaluation when he was 25 months old. As in all previous evaluations, Raymond's birth mother was invited, but she did not attend. She had not attended any medical, early intervention, or other appointments. After his previous evaluation, he began to receive occupational therapy through EI. The SY reevaluation indicated that Raymond was benefiting from this intervention because his visual and motor skills progressed from a 47% delay at age 17 months to a 22% delay at 25 months of age. Speech-language skills continued to be age appropriate.

Soon after the reevaluation, the foster parents began pressing the department of human services to change Raymond's goal to adoption. After almost a year, a permanency hearing was held in Philadelphia Family Court with a major focus on the goal change. Raymond's birth mother contested this new goal, wanting to assume custody of Raymond. At the hearing, the director of the SY program testified that given Raymond's complex medical and developmental needs, he required a parent who would take him to all primary health care and medical specialty appointments, participate in EI treatment, take him for any therapeutic visits, adhere to treatment recommendations, observe his development over time, and advocate for health and special education services throughout his childhood. The court ordered Raymond's goal to be changed to adoption. Thereafter, his birth mother's parental rights were terminated, and Raymond was adopted.

PHILADELPHIA EARLY INTERVENTION CASE STUDY

The EI program is the richest entitlement that exists for our nation's most vulnerable children—very young children involved in the child welfare system. The research has demonstrated that children ages birth to 3 who have been maltreated are more likely to have fragile health and developmental disabilities and delays than any other group of American children. Yet, ensuring that these most vulnerable children are referred, screened, evaluated, and in receipt of the rich array of services for EI has been a Herculean task. This chapter traces the efforts of

professionals working in the health care, EI, and child welfare systems to make EI screening universal and EI services available to children associated with child welfare. After a decade-long struggle, positive steps have been made toward achieving this goal. Today, all identified children under age 5 in Philadelphia with open cases served by the child welfare system—children in foster care, children with substantiated cases of maltreatment living at home receiving services, and even children whose reports were unsubstantiated—are eligible for the Child Welfare Early Intervention Initiative (CWEII) developmental surveillance program. This program, developed after many refinements, provides developmental screening to all children known to the Philadelphia Department of Human Services (DHS), referral to EI for children with any suspicion of delay, and rescreening every 6 months of children under the age of 3 who are found ineligible as a way to track and monitor development to identify delays that emerged over time. This program's breadth is consistent with the recommendations of the Institute of Medicine and National Research Council's definitive guide to the research on early childhood, *From Neurons to Neighborhoods: The Science of Early Childhood Development* (Shonkoff & Phillips, 2000), and is far more encompassing than even the federal law provisions in the Child Abuse Prevention and Treatment Act (CAPTA) of 2003 (PL 93-247) and the Individuals with Disabilities Education Improvement Act (IDEA) 2004 (PL 108-446), which only target children involved in substantiated cases.

Yet, the genesis of the Philadelphia CWEII can be traced long before national attention formulated the new federal EI referral provisions. It began in the early 1990s as a concern of EI and health care professionals anxious to connect children in the child welfare system to important EI services. This is the story of that effort and the effective partnerships forged to make connection to EI a reality for Philadelphia's most vulnerable very young children.

STARTING YOUNG

The Starting Young (SY) program was founded and developed by Dr. Judith Silver after she had been working for years as a psychologist in neonatal follow-up programs in Chicago and Philadelphia (J. Silver, personal communication, April 10, 2007; May 8, 2007). While working in a hospital-based neurodevelopmental evaluation clinic in Philadelphia, Silver noticed that a large number of children in foster care were referred due to concerns about behavior problems and developmental delays. The majority of these children were 4 or 5 years old, and evaluations confirmed that development was delayed. Many had been prenatally exposed to crack and/or cocaine and most had entered foster care placement in the first 2 years of life. Yet, their caseworkers did not flag problems until the children were 4 or 5 years old, and the EI system, with its required Child Find resources, did not reach out to the county children and youth agency or to private child welfare provider agencies to encourage referrals to EI for this group of children.

Silver was concerned that infants in foster care were not accessing their entitlement to EI, despite their evident need. She believed that if these foster children could be reached in the first years of life through interdisciplinary evaluation, they could be evaluated and connected to important EI services that could address or ameliorate their delays. She seized the chance to establish such a program in response to a request for proposals (RFPs) from the Pew Charitable Trusts, and, therefore, wrote a proposal to establish SY.

SY was funded and opened its doors in 1992. It is a multidisciplinary, developmental diagnostic and referral service, which was created exclusively for infants and toddlers who receive services from the Philadelphia DHS, including foster care, kinship care, family preservation, or in-home child welfare services (Silver, 2002; Silver, Amster, & Haecker, 1999). The program's goal is to connect DHS-involved children who have delayed development with EI so that they can receive needed developmental, family support, and other services. The SY interdisciplinary assessment team is composed of a pediatrician, as well as a child psychologist, speech-language pathologist, physical therapist, and an intake worker from Child Link, the EI coordination agency of Philadelphia (Silver, 2002). The presence of the EI worker is a critical innovation of SY because his or her attendance smoothes enrollment into the EI program and also provides a link for the children's caregivers. The actual intake interview is conducted by a pediatric social worker who also arranges referrals.

After completion of the interdisciplinary, comprehensive evaluation by the SY team, the entire team, including the EI worker, reviews the results and makes recommendations regarding the child's need for medical care, social services, and EI eligibility. The team's recommendations are discussed with the child's caregivers (biological parents and/or foster parents) and the child welfare worker prior to their departure from the clinic. Within a few weeks, the evaluation report and recommendations are sent to the child's biological and/or foster parents, child welfare worker, pediatrician, and, if necessary, the child's attorney. The program's caseworker follows up with the foster or biological parents within 8–12 weeks to encourage adherence to recommendations. Children are reevaluated every 6 months until they are 30 months old.

SY data underscores the importance of its service. Many of the children did not have adequate contact with their primary health care providers, with 22% needing immunizations and 20% presenting with growth delay. More than 40% of the children had health problems warranting referral to medical specialists. Approximately half of the children (49%) needed EI services due to developmental delays (Silver, Amster & Haecker, 1999).

The ability to produce a high-quality, multidisciplinary evaluation that is acceptable to EI in conjunction with the participation of an EI worker on the team facilitates the connection of children to this vital service. In addition to providing clinical evaluations, the SY team annually provides at least three full-day workshops for child welfare professionals on identifying the health and developmental

needs of infants in foster care and how to obtain community-based services (including EI).

In the mid-1990s, as those involved with the child welfare system began to see the merit of the SY approach, not only did referrals increase but also team members were invited to participate on various initiatives focused on children in foster care. Requests for information and assistance came from senior administrators and provided an opportunity for the SY team to educate child welfare professionals about the health and developmental needs of children involved with DHS, which resulted in requests for training of public and private child welfare agency staff and also helped Silver and her colleagues become connected to the wider world of child welfare in their region.

These new contacts led to invitations for the SY team to write about this issue (Silver, Amster, et al., 1999). Indeed, finding a dearth of written materials about the health and developmental needs of young children in the child welfare system, Silver accepted an offer to edit and shepherd the first book published on young children in the child welfare system that provides an interdisciplinary pediatric and developmental perspective. Published in 1999, Silver, Amster, and Haecker edited a volume titled *Young Children and Foster Care: A Guide for Professionals* that is a sourcebook for professionals on a range of clinical issues confronting young children in foster care. The book also became a connection tool for Silver and her colleagues. They not only wrote various chapters but also they were able to invite new colleagues from the academic, clinical, public, and private sectors to write chapters. This collaboration contributed to the creation of diverse partnerships in the Philadelphia region, as well as state and nationwide. *Young Children and Foster Care* remains the seminal text in this field.

EARLY ADVOCACY EFFORTS

The expertise and the contacts that Silver and her team were acquiring about young children in foster care inevitably led them to be invited to present at policy-focused forums and serve on city task forces. Perhaps the most significant invitation occurred only a year after SY opened its doors, when Trude Haecker, SY's team pediatrician, and Silver were asked to serve on a community task force created by the Pennsylvania Department of Public Welfare and Philadelphia DHS to shape the implementation of the Annie E. Casey Foundation's Family to Family Initiative in Philadelphia (Silver, 2002; J. Silver, personal communication, May 8, 2007). This participation made SY visible to an important group of child welfare leaders in the city, raising awareness that EI and health care services for infants and toddlers were seriously underutilized. It also enabled them to forge important connections and to establish SY's reputation as a key partner in the child welfare system. For Silver, developing working relationships with committed inside players in the field of child welfare was a significant outcome of her participation on the task force.

One of these connections led to Silver's participation in a key policy initiative concerning children in foster care. A DHS official requested her assistance in writing a grant to establish a step-down practice aimed at moving children with complex medical needs out of nursing homes and into less-restrictive settings. A large number of these children were very young, and many were placed directly from hospital NICUs. In helping to fashion the proposal, Silver urged the adoption of a case review system as the cornerstone of the project. She hoped that a multidisciplinary committee (including pediatricians, psychologists, and social workers) could work with DHS administrators and review the cases of every child in DHS placed in a nursing home and provide consultation on how to better meet their health, developmental, academic, and social-emotional needs, ideally in family foster care (J. Silver, personal communication, May 8, 2007).

The 3-year federal grant from CAPTA funds was awarded to Philadelphia DHS in 1993 and became one of the nation's first efforts to use a multidisciplinary review committee to address the needs of medically complex children in the child welfare system. Dr. Joseph Kuna, an administrator at DHS, chaired the task force known as the Medically Complex Multidisciplinary Review Team (MRT). Julie Alexander, a psychologist at DHS, also participated and eventually chaired the task force. Silver became a central player on this task force, which reviewed the cases of all DHS children with complex medical needs placed in nursing homes and made recommendations regarding improving the children's access to health care, awarding educational and disability entitlements, and stepping down to less restrictive settings—notably for family medical foster care. It was here that Silver, Alexander, and Kuna developed a good working relationship. Alexander says that it was here, too, that she learned from Silver about the needs of the youngest children in foster care. Alexander noted that Silver was a "central figure" in the MRT who conveyed the "urgency" of these young children's plights in a nonconfrontational way (J. Alexander, personal communication, May 7, 2007). Perhaps the greatest tangible policy achievement of this collaboration happened without anyone really noticing it and without any formal written policy. Philadelphia DHS ended the practice, which still goes on in other jurisdictions, of placing medically complex babies directly from NICUs into nursing homes.

SUBCOMMITTEE ON THE HEALTH CARE OF CHILDREN IN SUBSTITUTE CARE

In the mid-1990s, Haecker and Silver moved to the Children's Hospital of Philadelphia (CHOP). This provided SY a more visible and prestigious setting for its groundbreaking work and helped elevate the program in the eyes of the health care community (Silver, 2002). At CHOP, Haecker supervised pediatric residents, many of whom treated children in foster care. Heather Forkey, M.D., then chief resident (and who later would become the SY pediatrician), helped identify the medical residents' concerns about this population and conveyed them to Haecker.

Because of her prior experiences as the SY pediatrician, Haecker was able to help focus residents' frustration concerning a myriad of problems and group these problems into the three categories of 1) accessing medical records, 2) securing consent for treatment, and 3) confusion regarding confidentiality issues involving children in DHS's custody.

Haecker encouraged Forkey to contact Margaret Zukoski at the Children, Youth and Family Council (a consortium of private child welfare provider agencies), who was the former social worker at SY (H. Forkey, personal communication, December, 2007; M. Zukoski, personal communication, January 5, 2008). Zukoski then arranged for the residents to meet with a range of experts from lawyers to government officials to ask their questions and voice their concerns on these systemic issues. Frustrated, the residents began holding open meetings inviting all concerned with the well-being of children in out-of-home care to discuss these issues. This group became the Subcommittee on Children in Substitute Care, a part of the Pennsylvania Children's Health Care Coalition, a broad-based advocacy coalition (Silver, 2002). The Subcommittee included health care professionals, social workers from private child welfare provider agencies, a DHS administrator and nurse from its Health Management Unit, Philadelphia's director of EI services and children's mental retardation services, attorneys from the Juvenile Law Center (JLC), and a policy analyst from a consortium of private child welfare provider agencies. For the next decade, Silver played an active role as its sole staff member, booking speakers; taking critical meeting minutes; encouraging the production of publications, such as the *Health Policy Recommendations for Children in Substitute Care* (Subcommittee on Children in Substitute Care, 1999); recruiting new participants; and, most important, keeping the Subcommittee alive.

Moving from concern about individual cases to seeing the problems as systemic took a set course. First, the residents and the other participants on the Subcommittee discussed their own clinical work, heard from child welfare providers and legal advocates, examined SY data, and began seeing threads of common themes. Those threads identified that children in substitute care often were not even receiving basic health care or EI services as guaranteed by the federal early and periodic screening, diagnosis, and treatment (EPSDT) and EI laws. They were not receiving health care consistent with the standards of the American Academy of Pediatrics (AAP) and the Child Welfare League of America (CWLA). They discovered that health information was not being uniformly reported or gathered in an organized fashion in DHS files, and that DHS claims that information could not be shared with the doctors due to confidentiality were often erroneous, based on a long-standing practice but not law. Armed with this learning, the Subcommittee was determined to find a way to help child welfare professionals easily gather basic information about children entering substitute care. The members developed five basic questions for all involved with children in substitute care to ask.

1. Did the child's mother have any health issues during pregnancy?
2. Has the child ever been hospitalized?
3. Does the child have any medical diagnoses?
4. Does the child have any allergies?
5. Are there any medical problems that run in the family? (Silver, 2002, p. 49)

During the course of numerous meetings, the Subcommittee discussed how the questions could be integrated into the work of DHS investigators and case-workers. DHS agreed to add these five simple questions to an intake form and have this form placed in each child's DHS file and the foster care agency file as a starting point for health care information. Lourdes Rosado and her attorney colleagues from the JLC were key players in this effort as they researched consent and confidentiality issues for children in substitute care in Pennsylvania so that the effort could be instituted. Despite this early paper victory, the Subcommittee learned an important lesson—implementation is hard. Although the forms were vetted and available at DHS, the section related to the five questions was not being completed by DHS workers. DHS later issued written policy in 2001 that required that all of the forms be filled out and filed in DHS and agency files. Adherence, however, remained inconsistent.

Recognizing the difficulty of accomplishing one small task to better the health care of Philadelphia's children in substitute care only served to galvanize the Subcommittee. Instead of giving up, they expanded their mission. Convinced now that piecemeal remedies would not suffice, they decided to aim higher to reform the entire system. They formed a committee to draft a document that would contain concrete broad-based proposals for improving health care for children in substitute care. Forkey wrote the first draft of the document and then it was refined extensively by Rosado and her JLC colleagues. Because of the years of meetings, DHS was on board since the director of the medical unit played a key role in shaping the recommendations and gaining DHS support. It was published in November 1999 as the *Health Policy Recommendations for Children in Substitute Care in Philadelphia* (Subcommittee on Children in Substitute Care, 1999). It enumerated health care changes into three discrete categories to aid implementation: 1) laws, policy, and regulation; 2) child welfare practice; and 3) juvenile court procedures. For each problem, the recommendations listed the applicable solutions according to those three implementation categories.

The major recommendations included

1. Prompt, convenient access to physicians and other health care providers
2. Comprehensive physical health assessments and developmental and mental health evaluations for children on entering substitute care

3. Ongoing well-child and preventive health care that meets the EPSDT guidelines, including appropriate linkages to mental health, EI, and special education services
4. A records system to ensure that essential health information is collected, maintained, shared with appropriate parties, and transferred when children change placements, change health care providers, and/or leave substitute care (Subcommittee on Children in Substitute Care, 1999, p. 5)

In order to raise awareness of the issues, the draft of the *Recommendations* was distributed for endorsement to a range of private provider agencies, pediatric practices, and legal advocacy organizations. The published version includes endorsements by the broad-based membership of the Subcommittee, including not only CHOP and SY professionals but also child welfare, health care, and EI providers; legal advocates; and members of the Pennsylvania State Foster Parents Association. Indeed, the final *Health Policy Recommendations for Children in Substitute Care in Philadelphia* were unveiled at an event that included city officials and judges (L. Rosado, personal communication, January 11, 2008). This effort heightened awareness of the health needs of children in foster care and dovetailed with the related policy issues of the move to Medicaid Managed Care for foster children (M. Zukoski, personal communication, January 5, 2008).

The *Health Policy Recommendations* were published and widely distributed across the city and state to health care providers, child welfare professionals, judges, lawyers, and city and state policy makers. This document served as a springboard for discussion about reform with this array of stakeholders and helped to frame the Subcommittee's future work. It chose to focus its energies on three projects that directly flowed from the *Health Policy Recommendations*:

1. Development and adoption of a health passport for all children in substitute care
2. Creation and use of consent forms and mirror court orders (orders that reflect the components of the consent forms in the event the forms are not signed) in the juvenile court for consents, sharing of medical information, and obtaining EI evaluations
3. Establishment of policy and practice to connect all DHS-involved children to EI

During the next several years, the Subcommittee work would focus on these three initiatives. Each followed an unpredictable course.

Health Passport

The proposal for creation of a health care passport was a logical end product of the effort to develop a simple, accessible mechanism to gather and keep medical records on children in substitute care. It was one of the major proposals of the

Health Policy Recommendations. For health care professionals, access to this information was vital for quality care. Other jurisdictions were trying to develop health care passports as well, and the Subcommittee effort involved studying and glean- ing learnings from those efforts (McCarthy, 2002).

The Subcommittee effort kindled an awareness of the need for a passport by DHS, who worked closely with members to create a draft passport that was unveiled at the Subcommittee meeting in December 2000 (Subcommittee on Children in Substitute Care, 2000). The new system, however, depended on the presence of public health nurses to gather and document health care information. When DHS failed to obtain funding for those public health nurses, the initiative faltered. Forkey notes that,

At that time the computerized medical record was becoming the new standard, and further efforts on a paper passport seemed anachronistic.... [They] had (at that time) hoped to link the DHS computer record with the computerized medical record, but tabled that right away as security and interface concerns were too great, and [they] hoped that technology advances in the near future would allow such an integration. (H. Forkey, personal communication, January 14, 2008)

An electronic passport still does not exist, but the issue of health information remains a central focus of the Subcommittee.

Court Forms Initiative

The effort to implement consent forms and uniform mirror court orders in juvenile court seemed like a doable task to the Subcommittee. That, too, naturally flowed from the *Health Policy Recommendations* to provide comprehensive health care, assessments, and records for all children in substitute care. Led by Rosado, the Subcommittee drafted consent forms for parents to sign granting release of medical, mental health, EI, and other records to DHS, including AIDS and HIV test results, as well as authorization for EI and mental health evaluations. These consent forms were matched with mirror court orders enabling the juvenile court to authorize quickly the release of information or evaluations in instances of parental refusal. During the next year, Rosado and her colleagues shared drafts of these forms with judges, city solicitors who represent DHS on these cases in court, the child advocacy attorneys who represent the children, and lawyers for parents. Painstakingly taking into account all of the various comments and objections, Lourdes produced a final set of forms ratified by the Subcommittee.

Throughout this process, Subcommittee members met with the judge of family court (also called juvenile court) who was developing a model court under the federal Court Improvement Project (CIP). A centerpiece of the model court for dependency cases (so named in Philadelphia for abuse and neglect cases) was the institution of prehearing conferences on all new cases. All the parties—parents, lawyers, DHS child welfare caseworkers—would be present at the prehearing

conference where they could discuss the case at the outset. This discussion would include gathering information about the circumstances of the case and the needs of the parents and child. It would also formulate early agreements on placement, services, and the allegations of abuse and neglect as well as develop a discovery plan for the case's future. In other words, agreed-upon issues could be identified early, and contested issues could be flagged at the outset.

Rosado realized that these prehearing conferences could serve as a place to secure parental consent on the new forms. The prehearing sessions occurred in the courthouse, but outside of the courtroom and could be a uniform, non-threatening, accessible site led by a facilitator for explaining and filling out these important forms. Once these forms were finalized, Rosado, Haecker, Silver, and Bob Schwartz, Executive Director of the Juvenile Law Center of Philadelphia and a national leader in juvenile law, met with the administrative judge to obtain the judge's assent. She gave them her approval and instructed them to work with the judge who presided over the model court.

After lengthy discussion and review by the CIP committee, an agreement was obtained to pilot the forms in the prehearing conference setting. By April 2001, the forms were finalized, and by July, they were available in the prehearing conference room. Yet, gaining agreement, even from a key inside player such as the judge or the committee, did not guarantee success (L. Rosado, personal communication, January 11, 2008). Someone needed to be responsible for the forms and court orders. Someone needed to explain the forms to parents, request their signatures, and flag refusals so the court could follow up and, if needed, enter court orders. The facilitators who presided over the prehearing conferences voiced concerns that the forms added one more task to their already full plate and declined to facilitate the signing of the forms. The city solicitor reluctantly agreed to play this role, but the task was often overlooked in time pressed, prehearing conferences, so the information was not gathered. Without a responsible party, the initiative fell apart with ongoing, periodic efforts to resurrect it.

Connecting Children to Early Intervention

The third project of the Subcommittee—connecting young children in substitute care to EI—seemed the least promising venture in 1999. In fact, the court forms initiative was seen as the most promising path to connection with EI because lack of consent was viewed as the major barrier for these children. Although the *Healthy Policy Recommendations* specifically targeted linkage to EI (including recommendations about gaining consent from parents, educating caseworkers about developmental needs, and developing DHS policy for linkage), the other projects—the health care passport and court forms—were elaborated in greater detail in the *Health Policy Recommendations*, and a path for Subcommittee work and implementation seemed to be more readily apparent. EI seemed far more intractable; however, Silver and her colleagues began to explore this issue, too.

In 1999, Silver and her colleagues invited Denise Taylor Patterson, who directs Philadelphia Early Intervention Services, to join the Subcommittee (D. Patterson, personal communication, January 15, 2008). Patterson was a useful addition because she had worked in child welfare for more than 20 years, as well as heading the local EI program and being awarded a Pew Foundation Grant to provide outreach services to at-risk children. (Her Pew Grant was part of a series of grants in the 1990s that included SY.)

To underscore the issue as well as tap Patterson's position, it became important that every Subcommittee meeting contain a discussion of some facet of EI. Many of those early meetings focused on the consent hurdles—parents refusing consent for evaluation or services—and the need for surrogate parents to consent for children whose parents were unknown or unavailable. At that time, Pennsylvania, in contrast to other states, was barring foster parents from serving as surrogate parents for EI and special education. This was not just an intellectual issue, but also a real barrier to services. Since EI requires parental consent at every juncture in the eligibility and service delivery process, failure to obtain consent can close a case. Furthermore, if no surrogate parent could be identified to give the required consent, the likelihood of a child in substitute care ever securing needed EI services was nonexistent. Fortunately, during the summer of 2001, a breakthrough occurred. After years of advocacy, Pennsylvania, in line with other states, determined that foster parents could serve as surrogate parents and verbally advised the city of this change (Rosado & Siddique, 2001).

The new policy required Silver and other members of the Subcommittee to become involved with issues of training foster parents to become surrogate parents and working with EI on this endeavor. These discussions also brought Julie Alexander of DHS and Patterson and her colleagues at EI together to talk about the range of EI problems (Siddique, 2002). Those discussions between Alexander and Patterson and their colleagues recognized that—although anecdotes underscored that children were not getting connected to EI—real data was needed. Indeed, at this juncture, Patterson had begun outreach efforts to other required Pennsylvania children considered at risk for developmental delays (such as homeless children) by providing training to staff in homeless shelters. She also knew from her own experience as an assistant director of a child welfare agency before coming to EI that many children involved with child welfare had developmental delays and would therefore be eligible for EI services (D. Patterson, personal communication, January 15, 2008).

The EI and DHS government officials agreed to shepherd a data request through both systems. When matched, comparing children in DHS custody with children enrolled in EI from December 1993 to June 2001 supported the prevailing view that these children were not getting connected to services. Only 14% of the children matched (Siddique, 2002); thus, only 14% of children in foster care in Philadelphia were receiving EI services, far less than the almost half of children with developmental delays found by the SY data (Silver, Amster, et al., 1999).

Children were simply not getting into the front door of EI, which underscored the need for a more systemic focus.

The data highlighted the importance of the *Healthy Policy Recommendations* proposal for the Department of Public Welfare (DPW) to revise its regulations to require the referral of all children entering substitute care under age 5 for multi-disciplinary developmental evaluation for EI services (Subcommittee on Children in Substitute Care, 1999). This proposal was written a year before the comparable recommendation in *From Neurons to Neighborhoods: The Science of Early Childhood Development* (Shonkoff & Phillips, 2000). During the next several years, the Subcommittee would continue to facilitate interagency dialogue and make suggestions, often trying to shape the smaller issues—consent and surrogate parent training—while advocating for the larger policy effort to refer *all* children for evaluation (Siddique, 2002).

CHANGES AT DHS

Although the Subcommittee meetings involved discussion of specific EI problems, there were glimmers that something larger was occurring in Philadelphia. On December 21, 2001, the DHS Commissioner announced the creation of the Behavioral Health Services Support Center (BHSSC) within DHS (A. Martinez, staff memo, December 21, 2001). Only a few weeks later, Kuna, who would direct the new unit with Alexander as his deputy, would make a formal presentation to the Subcommittee (Siddique, 2002). As part of a larger reorganization effort combining access to mental health and intellectual disabilities services, as well as drug treatment for DHS-involved children and families, four support centers were created to help child welfare and operational staff and to provide consultation and connection to services for children. Although the discussion focused on older children, Alexander noted that they hoped to develop an early intervention unit to evaluate and offer services to children from 30 days to 5 years old. She also alluded to an attempt to work out a tool for universal behavioral health screening for children (Siddique, 2002).

Beginning in the mid-1990s, Kuna, Silver, and Alexander discussed the health and developmental needs of young children in the child welfare system. Kuna reports that his role has been to listen, learn, and try to champion those ideas within the bureaucracy (J. Kuna, personal communication, July 26, 2007). Those ongoing conversations influenced the planning stages for the new BHSSC unit. In the spring of 2001, Kuna asked Silver to draft a proposal for universal developmental screening for all infants and toddlers in foster care (Silver, Gerdes, & Haecker, 2001). The draft proposal acknowledged the importance of ensuring EI identification and intervention while warning that, without such an effort, children with unidentified developmental delays are at risk for placement disruptions and impaired school readiness. It also bemoaned the lack of screening resources in Philadelphia.

To address these concerns, the proposal called for screenings and linkages to evaluations for young children who are involved with DHS. The proposal underscored the importance of early screening because children are entering care with unidentified delays and disorders, which could place stress on the children and their families; contribute to placement failures; and also magnify children's developmental, emotional, and medical problems. The proposal urged a developmental screening program for all children entering foster care from birth to age 3. It suggested hiring infant development specialists, also called *early childhood developmental specialists*, who would be colocated at DHS and work closely with caseworkers. These new specialists would provide on-site screenings that would triage cases by helping to identify red flags for EI eligibility, such as growth delay, muscle tone abnormalities, NICU history, eye conditions, and poor hearing. These specialists would also provide guidance to families, referrals, and training, as well as technical assistance and consultation to DHS.

Silver and her colleagues proposed that each child should be screened within 45 days of entry into care through an hour-long, interactive process, which would include questions about the child's health and skills as well as an observation of the child playing, but would also allow time for counseling about the child's needs and for providing anticipatory guidance to the parent or foster parent. The proposal also contained an anticipatory guidance packet to be given to all foster parents, including a list of developmental milestones and red flags, handouts, and even toys. According to the proposal, all children would be screened, and if a given child failed the screen or evidenced a suspected delay, the child would be referred to EI for evaluation. The DHS would monitor the referral and evaluation services process, participate in the shaping of the service plan, add the results of the screen to the child's DHS plan and case file, and keep data on all referred children. Training for foster parents and caseworkers on infant development and the EI entitlement, as well as meeting young children's health care needs, would be a central role for the new unit.

The proposal raised the knotty question of the screening tool, suggesting that existing tools, such as the *Ages & Stages Questionnaires*® (ASQ): *A Parent-Completed, Child-Monitoring System* (Bricker & Squires, 1999), might be used with some modification. The proposal had blanks and questions directed to Kuna. Yet, after hurrying to produce the draft proposal, Silver never heard of it again. By the time Silver delivered the draft in May 2001, Kuna realized that the timing to advance the universal screening proposal within the bureaucracy was premature, so he waited for a more opportune time (J. Kuna, personal communication, July 26, 2007). Silver respected Kuna's political instincts and stopped pressing for the proposal. Indeed, at the time she didn't even know why the proposal was deferred, but she saw it as an exercise comparable to her trainings and the writings, similar to "planting a seed" (J. Silver, personal communication, July 27, 2007).

In the ensuing years, Silver would continue to raise the importance of EI for children in foster care in various forums. She received a 2005 federal grant to

create the Child Welfare Early Childhood Initiative at CHOP where she spearheaded an educational series for supervisors at DHS and its contract agencies, judges, attorneys, and court-appointed special advocates (CASAs). Every session emphasized the vulnerability of the youngest children in the child welfare system and their need for connection to vital services, with an emphasis on EI. She also continued to pepper Kuna and Alexander on the bigger issue—connecting children to EI—by keeping them up to date on legislative developments that would eventually become the Keeping Children and Families Safe Act (CAPTA) of 2003 (PL 108-36) and IDEA 2004 (PL 108-446) referral requirements (J. Silver, personal communication, July 25, 2008).

The Child Welfare Early Intervention Initiative

From 2001 to 2003, the new DHS unit, BHSSC, worked to become a strong citywide entity. Kuna wrestled with integrating county mental retardation services (MRS) with DHS. This integration with MRS was critical because it was the lead city agency for EI. Yet, the timing for the universal screen for DHS children still was not right. Only after the mantle of integration was completed and the federal mandates of the CAPTA 2003 and IDEA 2004 were passed could Kuna begin to move this issue (J. Kuna, personal communication, July 26, 2007). Indeed, the new laws “represented efforts to drive policy and program development to reduce risks of poor developmental outcomes among infants and toddlers in the child welfare system” (Alexander, 2004, p. 4), underscoring the Adoption and Safe Families Act (ASFA) of 1997 (PL 105-89) and its well-being requirements (Alexander, 2004).

As a result of years of internal and external work, a groundbreaking policy was issued in 2004: Philadelphia would be one of only a few jurisdictions nationwide to refer all children in the child welfare system to EI (Child Information Welfare Gateway, 2007). The 2004 directive established the CWEIF to be headed by Alexander. This directive was created by many factors—mandate of federal law, integration of the systems, and an increasing awareness of the prevalence of developmental delays and disabilities among DHS-involved children. It required all providers of in-home services to “work with parents, guardians and custodians to facilitate referral for developmental screening of all children birth to age 5 years” (Alexander, 2004, p. 6). This broad response to facilitate universal referrals recognized that the first 5 years of life presented an excellent opportunity to help mold, educate, and support a caregiver’s ability to augment their child’s development. It would also diminish the chances of future behavior and/or health problems, an underlying and cost-saving goal of the new agency. Thus, EI was a set of interventions that could add support for parents, sensitize caregivers, and reduce the risk of poor outcomes, thereby promoting permanency and well-being. The key referral source would be the private providers of child welfare services rather than child protective service workers, intake workers, or others employed by the city.

This was a practice meant to comply with the union mandate against more paperwork (D. Patterson, personal communication, January 15, 2008).

To implement this broad mandate, Alexander undertook several initiatives. She would develop a help unit specifically geared toward responding to problems with referrals from the field (Cohen, 2005). She further devised an elaborate data system that included a tickler system to track referrals and contact EI to follow progress and ameliorate problems. Training for both DHS providers and staff would ensure knowledge about the EI system. Thus, the universal referral policy furthered DHS's agenda and compliance with ASFA, as well as the other federal laws. By the summer of 2004, more than 600 referrals had resulted in completed IFSPs (J. Alexander, personal communication, July 26, 2007).

Despite the early glimmers of success of the broad mandate and the elaborate implementation strategies, referrals faltered. The system ran into unanticipated problems. Since all children were treated alike, children with the most urgent problems were no more likely to be referred than those without delays. Furthermore, DHS providers found making EI referrals difficult. Parents too seemed wary and unclear about EI. Despite the changes, foster parents were often still not permitted to sign consent forms, resulting in delays and EI case closures before evaluations could even occur. The data being reported were incomplete, so it was unclear how the system was working. In essence, the task of referring thousands of Philadelphia's children under age 5 involved in the child welfare system—there were 6,000 children in 2006—was trapped in a logjam (J. Alexander, personal communication, July 26, 2007).

Alexander and her colleagues determined that reform was needed, and in 2007, working very closely with Patterson and the EI staff, they began implementing the Developmental Surveillance project (Evans, 2006). The new policy required developmental surveillance for all children under age 5 known to DHS, a far broader category than the federal law requirement of children birth to 3 involved in substantiated cases of abuse and neglect. It would facilitate the use of the ASQ (Bricker & Squires, 1999) screening tool for all children under age 3 and, if no delays, again every 6 months. The broader purview for the screens was justified in the directive citing the high risk factors of those children and the importance of ensuring that all children who may have potential developmental delays are identified and receive EI. Trained DHS or provider agency staff would screen all children under 4.9 years of age in their home or foster home using the ASQ. Children in foster care would be screened within 60–90 days of placement. If the screen results flag one or more areas of potential delay, children would be referred to EI. In the event that no suspected delay is identified, the parent must be informed of the right to request an evaluation—a right embodied in federal EI law and critical for these children. DHS also requires documentation of all screenings and referrals.

To further open the logjam, full implementation of the provisions permitting foster parents to give consent to evaluation and services and to serve as

surrogate parents if needed would occur. The legal staff at DHS developed a procedure for securing court authorization, now permitted by IDEA 2004 in cases of refusal of consent where medical necessity dictated immediate connection to EI (J. Alexander, personal communication, July 26, 2007).

Most significantly, the developmental surveillance program would establish a triage system ensuring that the most urgent cases were referred to and served by EI. The new in-home use of the ASQ is designed to facilitate parental understanding of their child's delays. Asking specific developmental questions of the parent or foster parent and then together watching the child's performance has opened discussion of the child's real needs, rendering parents more receptive to the EI program and more willing to sign consents. In essence, they can witness the delays because the family is really administering the ASQ in concert with the caseworker (J. Alexander, personal communication, July 26, 2007).

An intensive training program has been presented to child welfare supervisors jointly by DHS and EI. It has focused on the urgency of addressing the needs of these children, but its most important component has been instructions on the use of the screening tool—a concrete topic that leads to enhanced skills to better understand the EI program. All supervisors were trained and, in turn, required to train their staffs. This enhanced professional development is an interesting side benefit of using the ASQ. For example, as child welfare caseworkers administer the ASQ with children's caregivers, they themselves will be learning more about early child development and have a means of better focusing on infants' and toddlers' functioning.

To further implement the policy, DHS and EI have executed an elaborate interagency agreement (DHS EI Interagency Agreement, 2006). EI is responsible for Child Find activities that include outreach to DHS. Upon referral, EI will perform intake as well as assign a service coordinator to the case. In turn, DHS, through its contractual agencies, will perform the developmental screens for all children and refer any child where “developmental concerns are identified” within 2 working days (DHS EI Interagency Agreement, 2006). The process for referrals was delineated and included faxed referrals by DHS to EI. EI will then contact the family within 48 hours or, if there is no phone, DHS will facilitate a joint home visit. If contact with the family is lost, EI will contact DHS, and EI will keep DHS apprised of the process and advise DHS once the evaluation is complete. Parents will be asked to sign a release permitting DHS to participate in the IFSP meeting. Most significantly, for the future, DHS and EI agree to provide joint training and share each other's mailing lists and notices. Monthly troubleshooter meetings are led by Alexander and attended by Patterson. The initial results have been promising despite problems in the training, consistent use of the ASQ, and hurdles at the referral site (M. Zukoski, personal communication, January 5, 2008). In the first year of operation, more than 1,000 children with open DHS cases have been found eligible and actually enrolled and were receiving EI services. More tinkering is needed to increase the number of well-

documented referrals. Underscoring the importance of the Philadelphia universal screening policy, the state of Pennsylvania has now adopted a similar directive requiring developmental screens for children under age 3 (Gold, 2008).

The idea of universal screening for all children touched by DHS was, of course, the brainchild of the Subcommittee as early as 1999. Silver's 2001 proposal informed the design of the CWEII, even suggesting use of the ASQ and the idea of rescreens every 6 months. Indeed, the seeds of a court-ordered mechanism to override refusal of consent were planted by the Subcommittee's court forms initiative. According to Alexander, the universal developmental surveillance program is the result of both "top down and grassroots" efforts. It needed not only the many seeds planted by Silver and her colleagues but also the political will and managerial expertise at DHS and EI to make the proposal a reality.

SCANDAL AND CALLS FOR REFORM

The backdrop of the child welfare system since the 1800s has been the interplay between scandal and reform. Most scandals have been precipitated by the death of a child, followed by blue ribbon commissions, expert panels urging change, and litigation. Since the mid-1980s, Philadelphia has seen several cycles of this pattern. The latest scandals surfaced in the fall of 2006 when the *Philadelphia Inquirer* began a series of articles focusing on deaths of children known to DHS. In response, the mayor followed a set course; he appointed an expert panel called the Philadelphia Child Welfare Review Panel. The panel, composed of national and local experts and a battery of staff, met for several months to conduct case reviews and interviews with DHS officials and focus groups of parents, caseworkers, and other system players. They also held a series of town hall meetings with parents, officials, and experts, including the Subcommittee, who all presented testimony.

On May 31, 2007, the panel released its report, titled *Protecting Philadelphia's Children: The Call to Action* (Spigner et al., 2007), calling for major reform at DHS. Although it highlighted the importance of leadership and development of a mission statement, its core recommendations were for an overhaul of child protection investigations and follow-up to protect the safety of Philadelphia's children. It emphasized a fact highlighted by this book—that virtually all of the child fatalities involved children under age 5, and two thirds involved children under age 1. Indeed, it found that of the 52 children who died from 2001–2006, 36 were under 1 year of age and 13 were just under 3 months of age. Yet, the majority of the families were known to DHS and more than half received child welfare preventive services.

The report emphasized that "infants were the most likely to die" (Spigner et al., 2007, p. 8), in part because of the inability of workers to flag medical problems and because of a lack of understanding both of medical information and of the need for health information about the infants. To respond to this dire

situation, the panel recommended a new protective services focus on children under age 5, including a face-to-face immediate interview within 2 hours of receiving a report of suspected child abuse or neglect involving a child under age 5 and a monthly face-to-face contact with a child under age 5 of any founded report. These face-to-face contacts are required to observe the “condition, safety, and behavior” (Spigner et al., 2007, p. v) of any child under age 5.

Yet, the report makes no recommendations about the content of those face-to-face contacts, the training required for staff, or even the requirement that experts in infancy and toddlerhood be involved in shaping the safety assessment instruments, training, or consultation. Ironically, although focusing on children under age 5, it neither mentions the DHS CWEII to screen all children under age 5 with open DHS cases or even the EI program. The mayor appointed a Community Oversight Board to report periodically on the recommendations. Those reports have also failed to mention EI or the CWEII (Community Oversight Board, 2007).

Paradoxically, EI could provide the richest array of services to those who were the focus of the report. This disconnect between meeting the real needs of these children and understanding ways to address these concerns continues to haunt the child welfare system as evidenced by the panel’s report. For example, the panel did not even learn about an internal report from DHS showing that children in long-term foster care displayed developmental delays in the early years (Elfman, 2007), and it ignored an ongoing effort, the CWEII, which could be deployed to promote the healthy development of Philadelphia’s most vulnerable children—its youngest children in the child welfare system.

LESSONS LEARNED

Despite the turmoil in child welfare in Philadelphia, the CWEII survived the change in administration in 2007. Indeed, Kuna now directs the Support Center for Family and Child Well Being that combines health and behavioral services for all children with open DHS cases, further addressing the Subcommittee Health Policy recommendations of 1999 (J. Silver, personal communication, November 10, 2008). The CWEII’s survival seems axiomatic given its deep DHS staff commitment and support from outside advocates, including Silver and the Subcommittee. Moreover, it has enhanced the involvement of unionized staff due to the union involvement in every step of the development of the CWEII. This is significant because the union is a central power in Philadelphia.

Interestingly, as the spotlight remained on the panel’s recommendation, Silver continued doing her training and education work. Under her federal grant for the Child Welfare Early Childhood Initiative at CHOP, she trained child welfare supervisors, lawyers, and judges, thereby laying the groundwork for implementation of reforms. This effort reopened the court forms initiative and now new judges are working with Rosado and Silver and the SY team to use those

court forms in child abuse and neglect proceedings. In addition, Kuna's new expanded role is bringing renewed interest to the Subcommittee's recommendations on health care records. Thus, the interconnection of all of these efforts is critical and underscores recognition of change as a long-term process.

The effort to get the Philadelphia child welfare system to focus on young children and connect those children to the vital two-generation entitlement of EI was shaped by a myriad of factors. First and foremost was the long-term commitment of Silver and her colleagues to this issue. They never wavered in making the needs of young children paramount. They never changed their focus to adolescents or children leaving care or children needing adoptions—all laudatory goals—but steadfastly concentrated on addressing the needs of the youngest children. Prolonged activity is at the heart of this success.

In addition to a decade-long commitment to reform, Silver and her colleagues inside and outside government never wavered in their proposed solution—the need to connect children to EI services. Again, they didn't invent a new remedy, but believed that EI provided the cornerstone for addressing young children's needs. Their efforts were multistrategic and seized every opportunity to create reform—proposing written recommendations for reform and court forms for consent; changing state policy to allow foster parents to consent to EI and also serve as surrogate parents; providing training to everyone who touches a child welfare case, including caseworkers and professionals in the fields of health care, early intervention and child care, judges, lawyers, and CASAs; writing articles and books; creating a new agency; drafting proposals for universal screening; and, finally, developing and refining a universal developmental surveillance program.

Each of these initiatives required commitment and skill from players inside and outside of government. Silver and her colleagues brought a wealth of professional expertise to the table, but without the managerial skill and dedication of Kuna and Alexander, their proposals would not have reached fruition. Indeed, Kuna and Alexander were informed by the draft proposal, but had to shape an initiative that would fit at DHS. Both inside and outside partners needed each other's expertise, political savvy, and perseverance. Only time will tell if the universal developmental surveillance system triumphs and truly identifies, refers, and connects children to vital EI services.

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