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by

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With appreciation to the parents
who shared so generously
of their time, understanding, and experiences.

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Abstract:

In recent years the number of children diagnosed with Autism Spectrum Disorders (ASD) has skyrocketed. In New York City this influx of children needing special services and special education has coincided with changing special education priorities and a major overhaul of the public school system. Added to this has been a lack of knowledge or agreement about the most effective interventions and teaching approaches for children with these disorders.

Six parents, each with a child aged five to nine-years-old with an ASD diagnosis, were interviewed and asked to describe their experiences with Early Intervention, and with CPSE and CSE interactions, services and placements.

The interviews were audio-recorded and transcribed. Although five out of six of the parents in this study indicated that they were relatively pleased with their child's current educational placement, each described years of challenge, stress, financial burden, and frustration trying to obtain an "individualized" and "appropriate" education for his or her child. Based on their unique experiences these parents offered advice to new families just entering the EI, CPSE and CSE systems, and suggested steps the Department of Education could take to improve the process of educating children with Autistic Spectrum Disorders, and working with their families.

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Rationale:

A number of considerations influenced my choice of this research topic. As a dual degree social work and early childhood special education student, I have witnessed the tensions that can arise between parents and educators: Parents know their children best and are the most important people in their children's lives. But, the education system -- including often very caring and capable teachers – also has a critical role in children's lives. In my own experience as a social work intern, I have sat through a CSE meeting with a parent who felt humiliated and unheard by the committee. But as a student teacher, I have also seen a parent respond harshly to a teacher who was going to great effort to be responsive to that parent and her child. Who is to blame? Obviously, it is pointless to generalize. Feelings about the welfare of young children run deep, both in parents and educators.

In my experience, these tensions can become even more pronounced when a child has a disability. Parents of such a child typically experience increased stress, anxiety, exhaustion, and financial burden. Added to this is their sense of urgency that their child receive the best possible educational services.

Nowhere is this urgency more apparent than with children who have Autism Spectrum Disorders. Research findings in the last decade point to the critical need for early, effective interventions for these children, and a majority of children who receive such interventions are progressing in ways not before thought possible. However, until recently these research findings have been slow to reach public awareness, and the interventions they promote have had – and still have -- too few trained practitioners. Parents who believe that they must do all they can for their child before that child reaches age 5 or 6, are unlikely to interact positively with a school system that seems to delay or fails to provide all they feel their child needs. And, the educational system, even when it has a will to be responsive, is struggling to catch up with what is known and to finance what is best.

As I consider my own possible career path, I have thought about working in Early Intervention with parents of children with Autism Spectrum Disorders. I feel great respect for the parents of young children with ASDs that I have met. Among these parents are my nephew and his wife. Particularly in the early stages, when parents are just coming to terms with their child's disability, they need people who will stand by them and, if necessary, advocate for them. At the same time, and with one foot in the education realm, I wish I could do something to insure that these experiences – particularly the CSE experiences – become more cooperative and less adversarial. In my social work internship and in conversations with parents, I have never yet met a parent who didn't feel that the CSE was trying to limit his or her child's services and optimal development. Yet I have never worked with an educator who wasn't deeply concerned about the children in his or her class and anxious to give them his or her best. Somewhere between the home, the classroom and the committee room there is a breakdown.

Certainly the starting point — whether one wishes to work directly with parents or to affect the larger system – is understanding. Surveys can provide useful lists of parent complaints or educator concerns, but don't reveal the interactions and individual experiences that shape perception and attitudes. Thus, I undertook this study with the hope that by interviewing parents one-on-one, I would come to better understand their individual experiences, and find common threads that could be examined in light of the larger system.

One person's story is no more than that: a unique individual story. Yet as those of us in the social work and education professions carefully listen to the individual stories of parents, we will be in a better position to understand and work with those parents, effectively serve their children, and build bridges where they are so very much needed.

Introduction & Background Information:

Pervasive Developmental Disorders – characteristics & prevalence

The DSM-IV includes five diagnoses of pervasive developmental disorders (PDD's). These are autism, Asperger's disorder, pervasive-developmental disorder not otherwise specified (PDD-NOS), Rett's disorder and childhood disintegrative disorder (Tanguay, 2000). Rett's disorder and childhood disintegrative disorder have distinct symptoms and are rarely confused with the other disorders. However there is often overlap and confusion about the diagnoses of autism, PPD-NOS, and Asperger's disorder.[1] In recent years these three disorders have been conceptualized as a continuum of related diagnoses called Autism Spectrum Disorders (ASD) (Kabot, Masi & Segal, 2003). Along this spectrum children manifest differing combinations of symptoms, levels of intellectual functioning (from profound retardation to superior intelligence) and overall degree of impairment, but all exhibit basic disturbances in communication and social interaction (Lord & Volkmar, 2002, Kabot, et.al.).

By all accounts there has been a dramatic increase in the number of children diagnosed with autism. In the late 1980's, 4 to 5 per 10,000 children were thought to have the disorder (Blakeslee, 2002). However a large-scale 1996 study conducted in metropolitan Atlanta found that 3.4 per 1,000 children had diagnoses of mild to severe autism (Blakeslee). California's Department of Developmental Services reported a 273% increase in autism cases between 1987 and 1998 (Mestel, 2003). During the period from 1987 to 1994, this translates to an increase from 5.8 to 14.9 per 10,000 children (Blacher, 2002). And, in a review of 20 epidemiological studies, Tanguay (2000) found prevalence rates as low as 1 per 250 and 1 per 500.

One important reason for these increases is that, in most studies, the diagnostic

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[1] See Appendix G for DSM-IV diagnostic criteria for each of these five disorders.

criteria have expanded to include children along the full autism spectrum. Thus children with Asperger's disorder and PDD-NOS are now often included in autism prevalence rates. It is unclear whether or not this fully explains the striking increase in the number of children who are diagnosed. But, the resulting explosion of children eligible for and needing special education services is undeniable (Blacher, 2002).

Diagnosis and Intervention

Most clinicians are reluctant to diagnose Autism Spectrum Disorders in children under the age of two. However, recent research has focused on behaviors seen in very young children that may be precursors of autism. These include deficits in pointing, showing objects, orienting to name and looking at others, as well as lack of pretend play, delay or absence of spoken language, etc. The presence of these and other indicators now provides the basis for early intervention, with or without a formal diagnosis of autism or PDD[2] (Kabot, et.al., 2003).

Several factors still complicate the search for and agreement about optimal interventions for children with Autism Spectrum Disorders. Among these are the: 1) significant individual differences in symptom presentation and severity of impairment among children with ASD; 2) concern among professionals that parents are relying on Internet-obtained information that is not always scientifically valid and; 3) general frustration that scientific evaluation of educational programs and treatments has not keep pace with the need for information (Kabot, et.al., 2003).

Notwithstanding these difficulties, Kabot, et.al (2003) have identified six areas of

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[2] Asperger's disorder is not usually diagnosed until a child is at least 3-years-old. This may be because children with Asperger's disorder do not have the delays in language acquisition and lack of age-appropriate self-help skills that might otherwise trigger early identification.

broad agreement among scientists and professionals:

1) Intervention should begin at the earliest possible age
2) Intervention should be intensive
3) Parent training and support should be an element of the program
4) Curriculum should focus on social and communication domains
5) Instruction should be based on the principles of applied behavior analysis (ABA)
6) Special emphasis should be placed on teaching for generalization

Applied Behavior Analysis (ABA) is a program of highly intensive one-on-one discrete trial teaching. Lessons are clearly structured across behavioral objectives, and performance data is collected frequently and regularly to permit responsive modification of strategies (Kabot, et. al. 2003). In 1987 Ivar Lovaas of UCLA published the results of his seminal study on the effectiveness of intensive ABA treatment for autistic children. Each of the children in Lovaas's experimental group received 40 hours per week of one-on-one ABA instruction for two or more years, while control group children received 10 hours or less of one-on-one instruction per week. Of the 19 children in the experimental group, 47% achieved normal intellectual and educational functioning (as indicated by normal-range IQ scores and successful first grade public school performance). Another 40% were found to be mildly retarded and assigned to special classes for the language delayed, and only 10% were determined to be profoundly retarded. In contrast, only 2% of the 40 control group children achieved normal educational and intellectual functioning; 45% were mildly retarded and assigned to special classes for the language-delayed, and 53% were determined to be profoundly retarded (Lovaas, 1987).

Although Lovaas's high success rate has not been definitively replicated by other studies (Kabot, et.al. 2003), there is broad consensus that ABA is the treatment with the most scientific support (Blacher, 2002). In addition, recent research verifies the need for at least 20-25 hours per week of systematic instruction for young children with autism

(Kabot). With the provision of ABA services at the 40 hour per week level costing $40,000 year or more, the issue of hours (20 or 25 versus 40) becomes a critical one for families and school systems (Blacher).

Mandated Services and Educational Provisions:

Mandated services and educational provisions for children with disabilities -- and particularly children with autism -- are relatively new in our nation's history. With the Education for All Handicapped Children Act of 1975, school-age children with disabilities were first guaranteed a free and appropriate education. Schools were mandated to create an Individualized Educational Plan (IEP) for each child with a disability, and to educate children in the "least restrictive environment." The Education of the Handicapped Act Amendments of 1986, mandated services for preschoolers (children ages 3-5), and established a program to assist states in developing early intervention services for infants and children under the age of 3. In 1990, the Individuals with Disabilities Education Act (IDEA) added autism to the list of categories of children eligible for special education and related services. Congress reauthorized the IDEA in 1997, and added provisions to strengthen the role of parents and ensure that all children have access to the general curriculum and reforms (Yell & Shriner, 1997).

In New York, children are eligible for Early Intervention (EI) if they are under three years old and have either a disability or a developmental delay. A disability means that a child has a diagnosed mental or physical condition that leads to problems in development (such as Downs syndrome, cerebral palsy, autism, hearing impairment). A developmental delay means that a child is deficient in at least one area of development, including physical development, cognitive development, communication, social-emotional development, and adaptive behaviors (NY State Department of Health, Early Intervention Program, no date).

Thus, under these guidelines a young child with *either* an ASD diagnosis *or* who displays behaviors that could be precursors of autism (eg. lack of social connectedness, lack of language) should be eligible for Early Intervention services. In New York, Early Intervention is under the administration of the Department of Health.

Children may be referred to the Early Intervention Office by their parents, pediatricians, child care workers, etc.[3] Parents are then directed to an agency which provides a free evaluation of their child. Once a child is found to be eligible for services, Early Intervention staff meet with the parents to discuss child and family needs, and to develop an Individualized Family Service Plan (IFSP). For children along the ASD continuum, IFSP-mandated services generally include speech therapy, occupational therapy, physical therapy and ABA, all of which are typically delivered in the home. However as recently as 6 years ago, when some of the parents and children in this study were entering the system, ABA was neither endorsed nor provided by Early Intervention.

Once a child turns 3-years-old, he or she comes under the jurisdiction of the Department of Education. This happens in a couple of different ways: 1) if the child is already receiving Early Intervention (EI) services, the EI service coordinator assists the family in transitioning to the school district's Committee on Preschool Special Education (CPSE); 2) if the child has not been receiving EI services and a disability is suspected, parents, doctors, teachers, etc. may refer the child to the CPSE for evaluation. Following the evaluation, parents are invited to meet with the CPSE, and if the child is eligible for services, an individualized education program (IEP) is developed. At the preschool level children with autism and PDD-NOS are most typically offered placement in a special education preschool, or attend a community preschool and receive special education

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[3] In New York City, a call is made to the NYC Department of Health Early Intervention referral line 1 (800) 577-2229

services at home. In the latter case, children may be eligible to have a Special Education Itinerant Teacher (SEIT) with them while they are at preschool.

Once a child turns 5-years-old, he or she comes under the purview of the Committee on Special Education (CSE), which has responsibility for children with disabilities ages 5 to 21. Both the CPSE and CSE guidelines call for an annual review of the child's IEP, and invite parent input and participation in this process. Once a child is in the CSE system he or she will be reevaluated at least once every three years. Within the New York City Department of Education, children with autism or PDD-NOS are likely to be placed in an inclusion class with a para, or assigned to one of the "District 75" schools. These are special education public schools, and offer classes with student to teacher to aide ratios as low as 6:1:1. When parents are able to demonstrate that Department of Education facilities are inadequate or inappropriate for their child, the Department of Education is required to fund placement at a non-public school (NPS) (The University of the State of New York, et al., 2002).

Unstated in the orderly process described above, are the emotions, disagreements, differing philosophies, and lack of clear communication and information that have characterized interactions between parents and EI, CPSE and especially the CSE administrators. In interviewing parents I hoped to better understand these difficulties and get a sense of what might improve the process.

Methodology:

To recruit study participants, phone calls were made and follow-up emails sent to representatives of four area associations for parents of children with Autism Spectrum Disorders.. Organizations contacted were the Queens and Manhattan chapters of the Autism Society, the Grace Foundation on Staten Island, and Parents of A.N.G.E.L.S. in the Bronx. The follow-up email included a letter which explained the project and requested parent volunteers (See Appendix H).

Over the next several weeks eight parents responded, six of whom were interviewed. Of the two parents not interviewed, one had not yet gone through the CSE transition as her child was only 4-years-old. The other parent had a difficult work schedule and we were unable to arrange a meeting during the interview period.

Prior to arranging the interviews, I spoke with each parent to explain the project and confirm his or her willingness to be tape recorded. Appointments were scheduled at times and in locations selected by the parents. Interview sites ranged from home (2 parents), to office (2 parents) to restaurant (2 parents) settings.

Of the six parents interviewed, all were Caucasian, and five were female and one was male. Three lived in Manhattan, and one each lived in the Bronx, Queens, and on Staten Island. Although none of the families were living in poverty, four mentioned the financial challenges associated with getting appropriate services for their children. In particular, two talked about loans they had obtained from family members, and of having to "max out" credit cards, second mortgage their home, or borrow against a pension plan in order to pay for home therapies and/or private school placements. Two parents spoke of their realization that they were "fortunate" to be able to pay for a particular service or hire an attorney, and expressed concern that there are many parents who can not afford to do these things.

Two of the female interviewees were not employed outside the home, although one of them was a part-time graduate student, and the other was heavily involved in a local autism association. This second parent also reported that her husband is a New York City Police Officer. Of the three women who were employed, one worked part-time for an educational foundation, one was a 3rd grade public school teacher, and one -- the only single parent -- was a company vice president. The male interviewee was an attorney with a small solo practice.

The children who were the focus of the interviews ranged in age from 5 to 9-years-old. Four were male and two were female. Each of the children had at least one sibling. In one case, the younger brother of the target child also had also been diagnosed with PDD-NOS.

Family	Parent gender & marital status	Age, gender & birth month and year of target child	Other children in the Family	Residence
A	Female, M	7-year-old male (June1996)	5-year-old male with PDD-NOS	Manhattan
B	Female, M*	9-year-old female (October1994)	6-year-old male	Staten Island
C	Female, M	8-year-old male (April 1995)	6-year-old female	Queens
D	Female, S	Almost 6-year-old male (December 1997)	3-1/2 year-old male	Manhattan
E	Female, M	5-year-old male (August 1998)	9-year-old female	Manhattan
F	Male, M*	9-year-old female (February1994)	6-year-old male 11-year-old male	Bronx

Figure 1: Family demographics Note: The families are arranged in the order visited

* The starred parents are the ones who talked most extensively about the financial strains they had experienced and their need to borrow from relatives, "max out" credit cards and/or borrow against pension plans to pay for their child's services and/or attorney fees.

Each appointment began with introductions and explanations, and with the parent reading and signing an Informed Consent Form (See Appendix I). The actual tape-recorded interview consisted of six open-ended questions. For purposes of comparison, it was important that each parent respond to the same set of questions. However, it was also anticipated that each parent would have his or her own unique experiences and thoughts to share, and that the open-ended question format would best encourage these contributions.

Questions:

1. How did you first realize that something was wrong?

This question led to a description of each child's early development and each parent's process of realizing that something was amiss. Responses also illuminated the confusion and frustration several parents felt as they had difficulty persuading their pediatricians that anything was wrong. This discussion led directly into the Early Intervention referral and the second question:

2. Tell me about what happened with Early Intervention?

In addition to talking about interactions with therapists and service coordinators, and about services their children received, parents also described the sense of urgency they felt to learn all they could about autism and effective interventions.

3. What was it like when you transitioned into CPSE?

At this point parents talked the CPSE transition, about their children's preschool-age services and placements, and about how the CPSE experience differed from EI. While most parents had clear memories of this time, a couple reported somewhat vague recollections. As one mother explained, she was so overwhelmed at the time, that she has forgotten a lot of what went on.

4. What happened when your child transitioned into CSE?

This seemed to be a topic parents particularly wanted to discuss. Earlier, while talking about EI and CPSE, more than one interviewee said, "But it was nothing compared to what happened when we got to CSE." Although the majority of parents reported being relatively pleased with their child's current school situation, each talked about the stress, anxiety, and often "fight" that proceeded this placement.

The final two questions were more global in nature, but seemed to flow naturally out of the course of the discussion:

5. If you were talking with parents who were just starting out in the EI system, what advice would you give them?

Interviewees appeared uniformly eager to pass on their knowledge and experience to others, and shared many excellent ideas. They spoke of their own development -- of their memories of feeling overwhelmed and isolated, and of how they had grown and changed.

6. If you could change something about the CPSE/CSE system, what would it be? What would make it all work better?

Most parents spoke at length and with passion about changes they'd like the Department of Education to adopt. Interestingly, each response was unique. Taken as a whole they give a broad picture of the experiences and concerns of the parents in this study.

The interviews lasted from 1 to 1-1/2 hours -- with most running closer to an hour. One interviewee had to leave to take her son home before she could answer the final two questions. She later answered these via email.

The audio recording of each interview was transcribed. These transcriptions are included in the appendix. While preparing the transcriptions, I came across several items which merited clarification. In each case, follow-up email (or telephone) questions to the parent, along with the parent's replies, are included at the end of the interview transcript.

Discussion:

1. Early development of children with Autism Spectrum Disorders

Three of the six parents interviewed (A,B, & D) reported a "normal" first year of life and development for their child. Parents B and D qualified this assessment with the observation that they were first-time mothers, and might not have recognized subtle indicators of autism. Parent B first became concerned when her daughter didn't start talking during the months after her first birthday. When Anna turned two and still wasn't speaking, Parent B sought a neurological evaluation. Parent D first became alarmed when at age two her son "started going into his own world." This did not resolve over the next several months and, with her pediatrician's encouragement Parent D scheduled an evaluation.

In his first 20 months of life, Parent A described her son Eli as a social, outgoing little boy who actively used a vocabulary of about 30 words. "My nickname for him was . . . the 'Ambassador of Joy.'" At 20 months Eli had an "uncharacteristic" illness which was followed by several days of lethargy. Over the next few weeks, he lost all of his language, stopped wanting to draw and engage in imaginative play, and became clingy and withdrawn.

Parent E described a somewhat mixed picture. Although her son Jeremy looked at people's faces, responded to voices and seemed "typical" in many ways, she sometimes wondered if something was amiss. This concern heightened when Jeremy only acquired "like two words" in the months after his first birthday. Then, following a severe allergic reaction to his DPT immunization at 18 months, Jeremy "kind of went into this mode where he wouldn't look at you. He was lethargic." It was, Parent E said, as if this regression after the DPT reaction made "everything clear." She realized that Jeremy had not been pointing, that he didn't have a pincer grasp, and that he spent a lot of time opening and closing cabinet doors.

Only two parents, Parents C and F, said they were definitely convinced that something was amiss during their child's first year of life. Both spoke with pediatricians about their observations and concerns, and both were told not to worry, that "kids develop at their own speed." Parent C requested a hearing exam for her son Gary at age 3

Family	Early Development	When parents first suspect a problem & what happens after that
A	Normal development for 1st 20 months: outgoing, talking, "Ambassador of Joy"	Following an illness at 20 months, Eli loses language & imaginative play, and withdraws. Family referred to EI. After 2nd eval at age 2, Eli receives PDD-NOS diagnosis
B	At the time Anna's development appears normal. Parents' only concern is that she does not talk.	At age 2 when Anna still isn't speaking, mother takes her to a neurologist. Referred to EI. Anna is evaluated and receives PDD diagnosis
C	At 3 months parents realize Gary isn't responding to sound, & have his hearing checked. As the first year continues, Mother is concerned that Gary doesn't look at people or track things.	Mother repeatedly raises concerns with pediatrician, who reassures her that Gary is fine. When Gary is 14 months, mother requests an EI evaluation for him. No ASD diagnosis given at that time, but EI services begun. Evaluation at age 5-- autism diagnosis
D	Early on, parents feel Carter is fine, a bit of a "character" but "well related." His speech is unusual in that he pronounces words beautifully, but rarely says the same word a second time.	At age 2, Carter starts "going into his own world." Pediatrician suggests an evaluation, but parents are reluctant. Carter's withdrawal persists, and several months later parents have him evaluated. He receives autism diagnosis, but does not start EI as he is almost 3.
E	Development mostly normal, but Jeremy doesn't point or grasp objects. Minimal language acquisition between 12 & 18 months.	At 18 months Jeremy is hospitalized for a severe allergic reaction. Afterwards he is "lethargic," won't "look at you," etc. Referred to EI at around 22 months. Re-evaluated at age 2 and receives PDD-NOS diagnosis.
F	When Emily is about 10 months, parents notice that she isn't responding to her name or paying attention to things going on around her.	When Emily is 11 months, parents talk to pediatrician who tells them not to worry. Over the next several months, Emily regresses: stops trying to talk, & looks "through" people. At 18 months, evaluated by developmental pediatrician. Enters EI at 20 months.

Figure 2: Comparison of early development and initial recognition of a disorder

months because he wasn't responding to sound. In addition, during the course of his first year she reported to her pediatrician that Gary wasn't tracking objects, looking at people, or smiling. When Parent F's daughter was 10 or 11 months-old her parents reported to the pediatrician that she wasn't responding to her name or paying attention to people or things around her. Over the next few months Emily gradually deteriorated to the point that she lost the small amount of language she had begun to acquire, and "just looked *through* you." Both of these parents ultimately initiated the evaluation process for their children. Parent C referred her son for an EI evaluation, and Parent F obtained a referral for his daughter to be seen by a developmental pediatrician.

2. Early Intervention (EI)

A chronological look at the Early Intervention experiences of the families in this study, underscores the tremendous changes that have taken place within this system.

When Family F entered EI in 1995 they were assigned a service coordinator who they said, "knew absolutely nothing about autism." All of their requests for ABA therapy were denied and they were offered instead "generalized special ed" for their daughter Emily. Parent F said he asked what "generalized special ed" was, but never received a satisfactory answer. He was left with the impression that Early Intervention didn't have a clear plan or approach for servicing children with autism. Given their conviction that early intervention with intensive behavioral therapy was essential, Parent F and his wife declined the EI offer and hired their own ABA therapists. Their daughter Emily eventually received 42 hours a week of ABA therapy, at a tremendous cost to her parents. Parent F described EI's lack of responsiveness and knowledge about autism in 1995: "One person from Early Intervention told my wife that she hoped she was happy over the fact that she was damaging my daughter because she was refusing to do what Early Intervention suggested . . . How do you tell another human being that they're hurting their child because they believe something different than the established norm? And the interesting thing about it is that when we eventually did fight them [sue for reimbursement] . . . we found out that their 'autism expert' had not dealt with an autistic child in 27 years, and their program representative knew nothing about the programs that were out there. And these were the people who were telling us, 'this is what your daughter needs.'" Parent F and his wife sued EI and eventually received reimbursement for a "substantial" portion of the money they had paid for Emily's ABA therapy. However, Parent F noted that he and his wife are still paying back the money they had to borrow during that time.

The Early Intervention response was not appreciably different when Families B and C entered the system in 1996. The children in these families were offered standard packages of OT, PT, speech and special education, 12-15 hours per week. After extensive study, Parent B was convinced that ABA was the best option for her daughter, and her daughter's special education teacher, who had been using ABA techniques with Anna, agreed. However, EI declined the family's requests for ABA therapy. Family B hired their own ABA therapists at considerable financial cost and strain.

After beginning with a similar package of services, Early Intervention took a different course for Parent C's son, Gary. At age 2 his autistic behaviors became more severe and he was given a half-day placement at a therapeutic nursery. Gary continued to receive home services, and his OT, implemented some ABA strategies with him. Parent C saw these as effective with Gary, but could not get EI to fund ABA therapy for him. When asked if her EI service coordinator had been helpful during this time, Parent C responded, "Forget about it. We rarely if ever saw them." Just two years later, beginning in 1998, parents in this study reported considerably different Early Intervention experiences. Parent A's son Eli started out with a mix of OT, speech, and special ed. But after 2 months, his speech therapist recommended ABA for him, and the rest of his home team concurred. They urged Parent A to have Eli re-evaluated, with the expectation that a stronger (i.e. PDD-NOS) diagnosis would improve Eli's chances of obtaining ABA services. The second evaluation, which came just after Eli turned 2, provided the

	Child enters EI	EI Services Obtained	Comments, Assessment
A	Summer 1998 Around the time Eli turns 2.	Eli begins with mix of special ed, speech & OT. After 2 months, speech therapist recommends ABA for him. Team concurs and encourages mom to get another eval. Eli receives PDD-NOS diagnosis & EI agrees to fund some ABA. Eli begins with 10 hrs. ABA per week and eventually works up to the mid-20's. Continues to receive speech & OT at home.	Positive overall. Paternalistic role of provider agency. Helpful YAI service coordinator.
B	1996 Anna is 2.	Anna receives 15 hours of home services: 5 hours speech, OT, and special education. She responds best to the special ed teacher who is ABA trained. Family requests ABA, but EI declines to provide it. Family hires ABA therapists at their own expense.	At the time EI not supportive of ABA, & thus not helpful to them.
C	1996 Gary is 14 months	Gary receives OT, PT, speech and special ed services at home, 3 days a week. At 2, when more autistic behaviors become apparent, he attends a therapeutic school for half the day, and continues home services. No ABA provided, but family is beginning to ask for this.	Did not have helpful interactions with EI service coordinator. Parents felt they were on their own
D	-------	No EI services. Because Gary is about to turn 3, parents are advised to prepare for CPSE (get evals required by Bd of Ed, check out potential schools). Parents pay for some private ABA therapy.	------------
E	Summer 2000 Jeremy is 22 months	Jeremy starts with 12 hours of services (OT, PT, speech, special ed). When 2-yrs-old, receives private evaluation & PDD-NOS diagnosis. Dr. recommends & Jeremy gets 20 hours ABA,10 hours each of speech, OT & PT, and 10 hours SEIT at his playgroup. All 40 hours are fully funded by EI.	Had a very good experience with her EI agency Life Start
F	Fall 1995	Referred to EI after private eval when Emily is 20 months old. EI slow to respond & unwilling to fund ABA. Family obtains intensive ABA services for their daughter at their own expense. Sues EI and eventually receives partial reimbursement.	At the time, says EI was disorganized & unknowledgeable about autism & ABA.

Figure 3: Comparison of EI experiences of study participants

PDD-NOS diagnosis, and EI readily agreed to fund Eli's ABA therapy. Eli eventually received 20 hours of ABA therapy a week in addition to his other home services. Parent A's account is striking both for EI's willingness to fund ABA, and for the consistently positive experiences she reported having with her provider agency and EI service coordinator.

Parent E's son, Jeremy, entered EI in the summer of 2000. At the time he was 22-months-old and also had a "PDD-like" diagnosis. EI offered 12 hours a week of OT, PT, speech, and special ed. When Jeremy turned 2, Parent E had him re-evaluated. In addition to giving Jeremy a firm PDD diagnosis, the developmental pediatrician recommended ABA therapy for him. EI responded by providing Jeremy with 20 hours ABA, 10 hours speech, OT and PT, and 10 hours of SEIT services while he was at his playgroup. Like Parent A, Parent E indicated that her provider agency and EI service coordinator were knowledgeable and helpful throughout their EI experience.

Committee on Preschool Special Education (CPSE)

The parents in this study talked in varying detail about their transition from Early Intervention to CPSE. But, each characterized this as a stressful time. Parent F, whose daughter turned 3 in 1997, said he and has wife had to "fight" all over again for the same services they had been trying to get through EI. Although they were able to obtain a center-based placement for Emily in an ABA preschool, CPSE was unwilling to fund additional home services, particularly ABA. Parent F said that, in the CPSE view at that time, "ABA [was] the next best thing to witchcraft."

Parent B, whose child transitioned to CPSE just a few months later, had a similar experience. Anna was funded to attend an ABA preschool, but CPSE refused to pay for any additional home services. As they had done during the EI period, Anna's parents paid for the home therapies. This time, however they sued, and eventually received 100%

reimbursement from the Board of Education. Parent B talked about these experiences: "During Early Intervention I never fought for anything. I didn't know. I took what they gave me and paid out for the rest. By the 3 to 5 program, I went after them. . . . I won and then it took about two years to get a check. . . . I had to show every check [I paid out to therapists] . . . So it was a whole bookkeeping system. Quite frankly, most parents don't do this because they're overwhelmed. Living with an autistic kid alone is overwhelming. . . . But I was just determined."

Parents A, D and E transitioned to CPSE between 1999 and 2001. Notwithstanding the increasing services and ABA support CPSE was offering children by that time, these parents each talked about the difficulty of this transition. From Parent A: "The emotional characteristic of going from EI to CPSE is like out of a warm bath and into cold water. You're on your own, you don't have a service coordinator who is responsible for you. Now, the questions about services are only about the kid, they're not about the family. So you can feel sort of unguided . . ." As Parent D prepared for her first CPSE meeting, she recalled that she was "terrified because of hearing other parent's experiences." She added, "You really need to know what your options are before you go, and what your child needs before you go. They don't start offering you stuff that your kid needs. You've got to know. And that's scary." Parent E echoed these anxieties – her fear was that she wouldn't be able to obtain the services her son needed. Her response was to prepare extensively for the CPSE meeting, to talk with other parents and to literally rehearse possible scenarios with her husband beforehand.

In 1999, when Parent A negotiated placement for her son Eli in a center-based preschool, CPSE was still unwilling to pay for additional home services. The following year, when Parent A moved Eli to a local preschool (and was paying his tuition), CPSE funded 30 hours of SEIT services and home ABA, OT and speech therapy. One year later, in 2001 when her second son, also autistic, entered CPSE, Parent A asked for the dual program [school placement plus home services] and got it. "That's partly because of the political change that was happening on the other side of the table, and not necessarily because of us. . . There was a greater willingness to do that because other families had gone to hearings and prevailed."

Parents D and E's children also benefitted from these changes in the "political" climate and CPSE response. At the beginning of 2001, Parent D's son received placement at an ABA preschool requested by his mother and was given an additional 20 hours (15 hrs ABA, 2 hours OT, 3 hours speech) of home services. Less than a year later, Parents E's son was given 25 hours of home services, including 20 hours ABA. Because he was not in center based programs during this time, Jeremy was also given a full-time SEIT to accompany him through the pre-school day.

Committee on Special Education (CSE):

According to most parents in this study, the transition from CPSE to CSE introduced new challenges. Parent A explained: "When it comes time to transition to 5, that becomes much more intimidating because your capacity to get information about the options is – well certainly in late 2000 and the spring of 2001 when I was looking – nothing. There's no list. There's no publication. The best source of information that I found was looking in the [telephone book] blue pages and finding the listings of the schools. I called District 75, and got bounced among no less than six people – never got answers, never got material. I got some useful sources locally by talking to my neighbors . . . But that's an extraordinary way to get information. That's totally outside the institutional structure." Parent A said she simply wanted to come to the CSE committee meeting with some knowledge about the schools her child might be offered, and a sense of what might be best for him. When she asked if she could speak with the placement officer, she was told, "No, not until you've had your committee meting." Contributing to her stress over this lack of information was the fact that the CSE meeting would not be held until May. If she were offered an unacceptable placement for her son, that would leave little time to visit other schools, find openings, and come to an agreement with CSE before the beginning of school in September.

When Parent B's daughter turned 5, the CSE functioned in much the same way: "You could not go see any of the programs until the committee made a recommendation, which was not until school almost opened."[tense changes]

Both Parents B and C referred to the inappropriateness of CSE evaluations for their children. "Well I brought [my son] to the district office to have the evaluation," Parent C explained. "And, the first thing I told them was that he was autistic. And I asked, 'Do you have a closet?' You know, because they were going to test him in the kindergarten classroom – too much stimulation. 'Do you have a closet where you can sit with him, and do you have the appropriate tests? . . .And they said, 'No. We only have the routine test for IQ.' And I said, 'Well you're not going to get an accurate diagnosis of him then because you're not set up for it.' And she admitted to me, 'Well we're not set up for it.'" At this point, Parent C opted for a private evaluation of her son. Because cost was an issue and she didn't want to deal with trying to get reimbursement from the Board of Education, she enrolled her son in a Prozac research protocol. This provided him with an appropriate and thorough free evaluation.

Although all but one of the parents in this study reported satisfaction with his or her child's current school placement, most have had to negotiate (or "fight" for) changes along the way. Parent A's son Eli was initially placed in a District 75 school, in a 6 to 1 to 1 class. From the outset, Parent A was concerned about the school's instructional philosophy, which was not behavioral. But this school seemed a better alternative than the other District 75 school in her area, which claimed to be doing ABA, but which seemed "very much like a work in progress." Parent A reasoned at the time, "I'd rather have no

ABA than possibly very bad ABA." Eli spent two years at his District 75 school, but before the end of the first year his parents were convinced that this placement was not a good fit for him. "We had a big paper record of the stuff we hadn't been happy with – which wasn't malfeasance on anyone's part. It was just not a good fit, not working for Eli. . . . In our second year there Eli began to have some problems in the classroom and he bit a couple of peers . . . He bit all three of the classroom staff that worked with him. We got him a one-to-one para. Actually, I think that was why Eli's May committee meeting was relatively easy: We had been there in November saying, 'we want a non-public school. This is not working.' And they said, 'well lets exhaust what we can do. Lets have a one-to-one first and see if that improves things.' And by mid-February we knew that while the one-to-one was helping, it was not doing enough. And so, when we came back [to the committee] we were a familiar file. We were a familiar case and they knew that we had already taken those extra steps." Following the May 2003 CSE meeting, Eli received approval and funding to attend a non-public school.

Parents B and C both visited the CSE-recommended District 75 schools, and found them to be inappropriate for their children. Parent C said, "They were . . . too noisy. Gary needs a lot of structure, and if it's too noisy he flips out. If it's too busy he flips out. The school like . . . forget about it. It was a loony bin. They had kids there ranging in age from 5 (and he would have been a 5-year-old) all the way up to 21. And I didn't think that was appropriate for all of them to be in the same building together." After declining several CSE-offered District 75 schools, Parent C found, through her NYFAC parent contacts, another District 75 school which turned out to be a good fit for Gary. It had the carefully structured environment and ABA instruction that he needed in order to function well. In his third year at the school, Gary developed a serious eating disorder. He has been able to remain at the school however, with a full-time health aide.

When Parent B visited the District 75 school recommended for her daughter, she had a different concern: there was no opportunity for inclusion.. "At the time, my daughter could speak. She could get her wants and needs known. She was toilet trained. She was ready for kindergarten. She knew all her shapes, letters, and all the beginning skills." Parent B then visited a second District 75 school, which would have offered the possibility of inclusion, but found the environmental challenges similar to those noted by Parent C: "They had three little SI III programs in the basement, but they'd go to the lunchroom with 200 kids, and had to walk through huge buildings to get there. It was totally inappropriate. . . . Everything is about environment with these children." With no other District 75 options available, Parent B enrolled her daughter in a small private school. There are 15 children in Anna's general ed class and, as far as Parent B knows, Anna is the only student with a disability. The children do a lot of one-on-one and small group work, and have frequent sensory breaks. Parent B described the class as quiet and orderly, said that Anna gets the extra support she needs from her para. In Parent B's opinion, this combination of appropriate environment and inclusion are just the right fit for her daughter.

Parent F reported that when his daughter transitioned into CSE in 1999, he still encountered some resistence to ABA. "If you mentioned ABA, they'd hear Pavlov's dogs - you're training her to be a circus act. You know, they'd just freak out over it. Ultimately we got them to agree to what Emily needed. But that was after a lot of kicking and screaming, hearings, having them held in contempt, and things like that." In all, during the EI, CPSE and beginning CSE years, Parent F said that he and his wife brought five court actions against Early Intervention and the Board of Education, "in order to get them to agree to give Emily what she needed."

By the time they approached their first CSE meetings, in 2002 and 2003, Parents D and E were able to benefit from the experiences and actions of parents who had gone before them. Each came to the CSE process well-prepared, having had consulted a lawyer and extensively researched school options. The CSE was still not giving out school information prior to the May meeting, but through discussions with other parents, therapists and teachers, and pre-contacts with schools, Parents D and E knew what placements they wanted for their children. During our interview, Parent D showed me a large spreadsheet on which she documented her school contacts during that time. "I have a whole file of who I sent all of Carter's reports to. . . . I probably sent out packets on Carter – like he was running for office – to 20 different schools." In her first CSE year, Parent D obtained pendency for Carter so that he could remain an extra year at his ABA preschool. She felt this was important as he had a December birthday and was benefitting so much from the program there. In her second CSE year, Parent D evaluated the schools on her spreadsheets, and was able to obtain placement for Carter at a non-public ABA-based school.

Parent E's first choice was for her son Jeremy to attend a public school inclusion kindergarten. However she was concerned that he would be offered a District 75 placement instead. So, prior to her CSE meeting, she visited several District 75 schools. "I did all my homework. I mean, they didn't even recommend schools, but I went and looked at the 6 to 1 to 6. I looked at the 12 to 1 to 1. . . . I felt so prepared . . . if they were going to say, 'He should be in a 12 to 1 to 1,' I'd be like, 'No way, because you're grouping kindergarteners, 1st and 2nd graders together. I went to see the classroom over there. There's no way I'm putting my kindergartener with a 2nd grader.'"

Parent E was able to obtain placement for her son, with a full-time para, in a public school inclusion kindergarten class. At the time of our initial phone contact and interview she was pleased with this placement and hopeful that it would work well for Jeremy. However, in email correspondences written 3 weeks later, she reported that the inclusion class did not seem to be a good match for Jeremy after all. "...there are TOO many students...23--even though there are two teachers. In my parent teacher conference this week I told the teachers to be truthful and honest . . .the class is too big for him, lunchtime is overstimulating." Parent E is now visiting private special education schools, and preparing to campaign for a non-public school placement for Jeremy next year.

To summarize current CSE placements of the children in this study: Children of Parents A, D, and F attend non-public (special ed) schools. These are fully funded by the Department of Education. Parent B's daughter attends a small private (general ed) school, with a full-time ABA-trained para. Parent B settled with the Department of Education for about 50% reimbursement of her daughter's tuition and para costs, however the Department is 2-1/2 years behind in paying her. Parent C's son attends a District 75 school with a full-time health aide. Parent E's son attends a public school inclusion kindergarten class with a full-time para. All but Parent E feel their children are appropriately and well-placed.

5. Advice to other parents

All six of the interviewees in this study spoke of how important it had been for them to network with other parents. For example: "Try to meet people who have been in your shoes, who've walked down that road" (Parent A). "Get yourself support. . . You need to put yourself with other people who are in your situation" (Parent B). "Listen to other parents and their experiences" (Parent D). However, Parent D added that hearing other parents' experiences can also be "terrifying." "It's a parent support group – but not what you'd expect, not like 'oh I'm going to go feel better.' It's not about you. It's about finding out how to deal with stuff and who to deal with, and exchanging experiences. . . . That has been really important for me." Parent F emphasized that one of the important functions of a support group is to help parents realize that they are not alone. "Because the first thing they feel is isolated. And I understand what they're going through, because I felt the same thing. . . . And you get the idea that nobody knows what you're going through, nobody understands what you need, and nobody really cares . . . The thing parents have to understand is that . . . there *is* a population of people that understand, and that [they] really are not alone."

Either in their advice section or earlier in the course of the interview three or more parents spoke about the importance of: 1) becoming educated about autism, interventions and school placements; and 2) keeping careful records.

Parent B talked about the value of attending workshops and seminars, and being trained in ABA. Parent C referred to the critical school information she obtained from other parents in her support group. Parent E recommended specific books and Internet sites, and Parent F spoke of the extensive library research he and his wife did in the mid-1990's (when Internet searches were not yet possible). All expressed the conviction that in order to choose wisely and advocate successfully for their children, they needed to know as much as possible about the issues at hand.

With regards to record keeping, Parent C explained that if you have recorded the names of people you have spoken with and kept notes on those conversations, you will be in a better position to address questions or inconsistencies that may arise during the CPSE or CSE meetings. "The documentation gives you power..." Parent E said that another parent helped prepare her for her first CPSE meeting and told her to bring a notebook with the IEP, information on the therapists, etc. "Show you're really on top of [things]." Parent C talked about knowing what you want and about going to the meetings with an "agenda." Parent E talked about literally rehearsing different scenarios with her husband before they attended their CPSE meeting.

Parents C and E also recommended that people bring a photo of their child to the committee meetings. "It gives a face to the person you're talking about. I don't like taking Gary physically with me because I feel that he disrupts the meeting. But if I have his picture sitting there, they'll see that the person we're speaking about is not a piece of paper. He's a living human being. This is the person we're talking about. This is my son. This is who he is" (Parent C).

Parents D and E urged people who are concerned about their child's development to not postpone getting an evaluation. ". . . just go get the evaluations if there is any wondering at all. . . Because the earlier, the better. I regret not knowing earlier" (Parent D). Parent C added, "If you're not satisfied with the results . . . you're entitled to as many evaluations as you want until you get what you think is necessary."

During the course of the interview, most parents spoke about the difficulty of finding and keeping home therapists. They cited poor reimbursement practices by the Department of Education (both low pay and lengthy delays in paying service providers), and therapist shortages. However, two parents also talked about the role of the family in building positive relationships with -- and keeping -- therapists. "I open my home to these people. I make them feel comfortable. They're part of my family . . . I buy them nice gifts. I do what I can. I tell them how much I appreciate what they're doing – whether it's this small or that much" (Parent B). "I'm constantly saying stuff like, 'Okay I got this catalogue. What toys do you want?' Or, 'I read this article. I'm passing it around to everyone.' Or, "You went to a conference. Can I have your notes?' It's a lot of open communication" (Parent E).

Parent A emphasized keeping in mind that "your child is supposed to get an *individualized* and *appropriate* program. If the program is not appropriate or not individualized, then it's not right. That's a federal entitlement."

Parent D talked about her realization that, she needs to "set aside" irritations and hurtful interactions with people who are involved in her son's care (or who make decisions about his services). "You're the advocate. I guess that's what it comes down to . . . it's not about you."

Parents E and F talked about accepting, loving, being realistic and celebrating. "No matter how much therapy your kid gets, no matter how much he knows or doesn't know, no matter how much he talks or doesn't talk – he is still your child and you love him for who he is" (Parent E). "Have realistic expectations. . . there are little baby steps forward, and there are a lot of giant steps backward, but it does happen sooner or later. Seven years ago [Emily] would take [a] sock, look at it, look at it, look at it, and not know what to do with it. You know, now she picks it up and she tells me, 'Sock on the foot.' So, it happens. And that's what I tell people. . . . You've got to wait for it, but it happens" (Parent F).

"Yes, there's a lot of grief involved with raising an autistic child, but make sure you celebrate all the successes. . . . If your success is that today your child picked up the spoon, dunked it in the cereal and then took a bite, celebrate that, because that was their goal for today and that's what they did. And if they do it tomorrow, give the kid extra cereal. . . . Celebrate" (Parent F).

6. What would improve the system?

Parents in the study responded quite differently to the question of how the CPSE, and CSE systems could be improved. Only two gave a somewhat similar response. Parent A said that the single greatest need is for "transparency"-- for parents to be given basic information. She particularly saw this as an issue at the time of the CSE transition. "My first experience of transition was, 'well we can't tell you.' The District 75 people didn't have a list of their own programs and the constituents in them. I just thought that was extremely improbable that they didn't have a catalogue of their own offerings somewhere, somehow." Specifically, Parent A suggested that "even the most rudimentary level of catalogue of what is available, programs and ratios, and maybe some aggregate data about what kinds of kids are in those classrooms this year . . . would be a tremendous help."

Parent D spoke more generally about a wish for more information at the CSE level. "It would be nice if there was some kind of guidance. Because everybody inventing the wheel is exhausting everybody." Parent D said she was recently contacted by the "teacher assigned for Carter's review team," and that this person called to ask if she could be of any assistance. Parent D said, "I was amazed. Somebody was calling me to tell me that if they could help me I should call them." She has since had another phone conversation with this woman, and received some helpful information from her. This is the first time Parent D has had a CSE member reach out to her in a pro-active, supportive way, and this was the only such CSE interaction reported in the parent interviews. Parent D urged more such contacts.

The remaining recommendations include Parents A's suggestion that the CSE meetings be held earlier in the year and not put off until May. When the CSE and parents disagree about placement, such a late start to the process of visiting alternative sites and trying to come to an agreement, is very stressful. "When we've been in situations where we might be in a public program in the fall or we might not, all the other families . . . they know where their kid is going to go in February."

Parent B urged the formation of smaller, less noisy, less crowded schools for children with autism. "These children should not be in gyms with other children. It is overwhelming. They should not have to walk from one class to another in large hallways with big people around. It should be a quiet little place where they can learn. And once you give them the proper environment and combine that with an ABA program . . . they can learn." Parent B also recommended that the Department of Education provide more opportunities for inclusion, and stronger staff training programs.

Parent C's suggested that the Department of Education "listen to the parents, because they know their child better than anybody else." Her sense has been that CSE is so preoccupied with budget concerns, that it doesn't necessarily "want to hear" what parents have to say.

Parent D advocated a careful thinking through of transportation issues and having more locally-placed schools. "You know, between Carter getting bussed by himself all year[4] so unnecessarily last year . . . It's like they have to have their rules, but come on! They have all these fiscal problems and just in terms of bussing that I know about myself -- the expense of bringing kids in and Carter out, and Carter by himself and all that -- could be classes, could be learning."

Parent E voiced a concern unique to this group, but likely shared by other parents of higher functioning children along the autism spectrum. She said the Department of Ed needs to come up with better options for the "in-between" children — children like her son Jeremy, for whom District 75 schools are too restrictive and inclusion classes (and typical elementary schools) are too overwhelming.

Finally, Parent F called for the education community to develop "an open mind" about how to educate children who are autistic, because "classic special ed techniques may not be the thing for [these] kids. . . . "My daughter is autistic. The child next to her is autistic. The two of them have drastically different manifestations of autism. My daughter is severely deficient in her expressive speech. I know autistic children that can converse excellently, but have other issues. Does it mean that one shouldn't get the intervention and the other should? No. They both need it, but they need different things. To say, 'We'll put them in the same class, give them the same program,' is ridiculous."

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[4] Parent D is referring to the fact that, because Carter stayed an extra year in his center-based preschool setting, he was considered "too old" to ride the school bus with the other children. Consequently he had his own bus – complete with driver and bus matron – to and from school each day.

Conclusion:

While a number of important themes emerged in the parent interviews, these must be considered in light of several significant limitations:

1. Study participants were all Caucasian. Without further investigation one cannot assume that their experiences mirror those of parents of other races.

2. Although there was some range in SES of the study participants, none were living in poverty. All but one of the parents indicated that they either had the means or were able to borrow the money to do what they felt was necessary for their children. It is unclear what services and placements their children would have received had these parents not been able to pay for a private evaluation and/or hire an attorney.[5]

3. All of the study participants were members of local autism associations. This suggests (and their own comments confirm) that they were receiving a level of support and information from other parents that factored into their negotiations and advocacy for their children.

4. Study participants not only volunteered for the project, but took the initiative to contact me and let me know of their willingness to be involved. This suggests (and interviews affirm) that each had a story to tell and that each had gone through some level of strife to procure appropriate services and placements for their child. What is missing from this sample are the experiences and perceptions of parents who have not felt at odds with the system, who have accepted and been satisfied with the placements their children were offered.

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[5] Chinini (1996) reported of talking with a New York City school official "who has sat in on days of special education meetings between schools and parents [and] says it all comes down to money: If the parents have good insurance or the money to get a 'favorable' diagnosis for their child, they come to the meeting armed for battle. They ague about what their kids deserve, present their medical information, and usually get a better deal than the district would have offered."

Keeping these limitations in mind, a number interesting findings emerged from the parent interviews. Number one and perhaps most encouraging is that the EI and CPSE systems appear to be changing, and becoming more responsive to families of children with ASD. In the experience of the study participants, EI, which in 1995 and 1996 denied all requests for ABA therapy, now routinely funds ABA. Whereas parents who entered the system in 1995 and 1996 described their EI service coordinators as "unhelpful" and knowing "nothing" about autism, the two parents (A & E) who most recently experienced EI spoke with appreciation about their EI service coordinators. They described these individuals as supportive, helpful and encouraging.

Although it is possible that the EI variations included a geographic component (the families who entered EI in the mid-1990's all lived in the outer boroughs), the evolution of CPSE services illustrates changes consistent across the boroughs: For example, in 1999, when (Manhattan) Parent A's son entered the system, CPSE was not funding home therapies in addition to a center-based preschool. (This had also been the experience of parents in the Bronx, Queens and on Staten Island, whose children entered CPSE before that time.) However when her second son entered the CPSE system in 2001, Parent A requested and received funding for a dual program (center-based preschool plus home services). This was compatible with the experiences of Parents D & E whose children were also given a full range of services in 2001.

Among study participants, a primary lingering concern about CPSE, is the Department of Education's poor system of reimbursing therapists. According to parents, not only are therapists paid less than they would otherwise earn, but the Department of Education is notoriously late in reimbursing them. While larger agencies can absorb this delay, individual therapists often cannot. Consequently a number of therapists do not accept Department of Education reimbursement. These are issues the Department of Education would do well to address.

According to study participants, CSE interactions continue to be troubling. One issue which complicates the CSE experience as much as any, is finances. When IDEA's predecessor, the Education for All Handicapped Children Act was passed in 1975, the federal government pledged that it would fund "up to 40%" of the costs incurred (Chinni, 1996). Although the proportion of federal government participation has gradually risen over the years, recent figures place the federal contribution at only around 18% (Kusler, 2003). As the parents interviewed are well aware, the cost for providing optimal services and placements for children with ASDs is staggering. Given the huge burden that has fallen on local and state governments, it is not unreasonable to assume that the CSE is under pressure to keep costs down. Unfortunately, and uniformly, the perception among parents in this study is that for the CSE, money issues take precedence over the welfare of their children. And, as has been the experience of the parents in this study, this perception often sets the stage for an adversarial relationship between parents and the CSE.

Parents in the study also spoke about their frustration at the CSE's failure to share information about school placements prior to the committee meetings, and at its practice of scheduling those meetings so late in the year. For these parents, the perception is that the CSE delays sharing information and giving out placements in the hopes that parents will just take what they are offered. Whether or not this is CSE's intent, the effect of these practices on parents in this study has been to strengthen their conviction that the CSE doesn't really care about the optimal (or even "appropriate") education of their children. In yet another way, an adversarial relationship is fostered between parents and the CSE.

Among the parents themselves there are differences of opinion about how children with ASDs should be educated. Parent B, whose daughter is functioning "beautifully" in a small inclusion class is convinced that, given the right environment, "inclusion is a must" for children with autism. For parents A, C, D and F, whose children are more severely impaired, inclusion is not the goal at this time. Parent E hoped that inclusion would work for her son, but has found that, at least in the large public school class setting, it does not.

The experience of each of these families has been that, the CSE routinely recommends placement in District 75 schools for children who are autistic. Yet as the parents have visited the District 75 schools proposed for their children, all have found them to be inadequate and inappropriate.[6] These schools have been, in the view of these parents too noisy, overwhelming and loosely structured. The comments of this sample of parents emphasize the unique characteristics and needs of each child with an ASD. Under the IDEA guarantee of an "appropriate" education for each child, it is imperative that the CSE demonstrates (and communicates to parents) a greater willingness to consider the specific needs of individual children.

Questions to be asked include:

1) In this time of so much change and upheaval in the school system, what plans and priorities are currently driving the CSE? Parent A was stunned to obtain non-public school placements for both of her sons during her May 2003 committee meetings. Did this, as she suspects, have something to do with the school system reorganization and "pink slips" that were affecting CSE members at the time, or is it evidence of changing attitudes within the CSE? How do the District 75 schools that were just rolling in ABA between 1999 and 2001 (and which appeared very inadequate to the parents who visited them at the time) look today?

2) While emphasizing well-delivered, empirically-supported instructional methods, can greater diversity (eg. of school environment, size & inclusion opportunities) be created

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[6] The one parent who eventually did accept and has been satisfied with a District 75 placement, learned about her son's school from other parents. Prior to obtaining placement for her son at this school, she had visited and rejected several District 75 schools offered by the then Board of Education.

among District 75 schools, to better accommodate the unique needs children with ASDs? While one child may be ready for limited inclusion experiences, another child may not be getting enough structure and support in even a 6:1:1 setting. A related question: What are the most appropriate placements for children (like Parent E's son), for whom District 75 schools are too restrictive, and standard inclusion classes (even with a full-time para) are too overwhelming? Is the Department of Education prepared to examine and support other options?

3) Should the Department of Education even be investing more in District 75 programs or should it fund additional non-public school placements instead? According to Parent B, the cost of educating a child for one year at her local District 75 school (including transportation and therapy expenses) is $60,000 per year. The annual cost of her daughter's tuition at a small private school, plus the ABA-trained para who is with her at school and the 10 hours of ABA therapy she receives at home is about $30,000. (Parent B providing her daughter's transportation). Assuming the $60,000 is even close to accurate, this is a stunning difference, and merits further study.

It is clear from the experiences of parents in this study that EI, CPSE and CSE are changing and that EI and CPSE, particularly, are offering greater support and services to children with ASDs and their families. It is also highly probable that some of the changes have come about because of the strong advocacy and litigation of these parents and others like them. Parents have fought for the welfare of their children at great cost however, not only financial, but also emotional. Parent F characterizes this: "I mean now-a-days things are a lot better than they were then, but essentially the main problem was not really dealing with Emily. That was the easy part. The problem was fighting the system that was out there, which seemed to not want to give her what it was that she needed."

It is the hope of this author that children with autism spectrum disorders in New

York City will receive the services and placements that will best enable them to reach their potential, and that parent-CSE interactions will become more cooperative and less adversarial. In part this is a matter of perception. As mentioned in the discussion section, Parent D was literally stunned when the teacher assigned to her son's review team, contacted her to see if she could be of some assistance. The CSE needs people like this contacting *every* family.

Clearly the cost of educating children with autism spectrum disorders is great. Yet, as the Lovaas findings suggest: early, intensive treatment can literally mean "normalization" – at least in terms of academic functioning and abilities – for many children. Ethically, emotionally, and ultimately even financially, these interventions seem well worth the cost.

Transcripts of Parent Interviews

Audio recordings of parent interviews were transcribed verbatim, with the following exceptions:

1) Filler expressions such as “uh” and “um,” “you know,” and “like,” were generally omitted.
2) Occasional minor changes were made in word order or verb tense when sentences would have been confusing without these changes.
3) Dots (. . .) Indicate either the omission of specific identifying information (eg. school location), or the omission of passages which were not considered germane to the focus of this study.
4) All names of individuals have been changed (or omitted) to preserve confidentiality. In addition school names have been altered to reflect the *type* of school rather than specific school identity. These are expressed as follows:

   SE Preschool - special education preschool (center-based preschool)
   D75 - District 75 (public special ed) school
   PS/I - Public school with inclusion
   NPS - Non-public (special ed) school

In addition, in most of the interviews, the current Department of Education is referred to as the “Board of Education.” Since this name change has come about only in the last year, most parents still refer to the Department by its previous name.

Transcript of Interview with Parent A -- "Laura"

"Eli" - 7-years-old (5-year-old "John" is also autistic)
This interview took place in Laura's apartment in Manhattan on 11/15/03.

[Introductory conversation in which Laura mentions Eli's "regression."]

S: Can you tell me more about that -- when you first realized that something was amiss?

L: Well Eli had very normal milestones of development for his first 20 months. He walked even a little bit early. He didn't show any motor irregularities. We did have difficulty with nursing at the very beginning . . . [more about that and her wondering if this might be significant] So he had very normal development except for this nursing difficulty. At the time of his regression, he had about 30 single words that he was using. My nickname for him was that he was the "Ambassador of Joy." He was very social and outgoing. He recognized and had definite signature interactions with different people in the neighborhood. At the grocery store the ladies would give him a cookie or a little box of raisins, and he knew that and worked them. . . . So we thought everything was very much on track.

Then in February 1998 we went to Florida to spend some time with my husband's parents. The week after we came back, Eli was ill -- a not characteristic illness for him, with vomiting and a slight fever. We went to the pediatrician to have him checked over, make sure he wasn't dehydrated, etc. They didn't see anything. They said, "Well this is probably viral. We don't really have anything to offer you." We gave him Pedialite and so forth and kept his diet very light. He was very lethargic over the next couple of days. Then those symptoms alleviated, but over the next several weeks his language faded out – almost in reverse of how he had acquired it. The most recent words went first, and the most established words seemed to go last. His social behavior changed drastically. In the middle of March he went to a child's birthday party. My husband took him to the party and Eli spent the entire party trying to leave, trying to get to the exit and just get out of there. This was not characteristic of him at all before. He quit having any kind of imaginative play or doing any kind of drawing with me. He became very clingy and he wanted to have a bottle *all* the time. . . . So we called the pediatrician. We said, "He has stopped talking. This is concerning to us."

And then we began a phase of medical investigation. Eli had an EEG and an MRI. Simultaneously the pediatrician told us to call the Early Childhood Direction Center. They referred us to Early Intervention. Somewhere along the line somebody clued us into a social worker at an agency who was sort of more senior, and who knew the whole system. And, with her advice, we pursued getting an interim IEP before we had really finished the evaluation. That was driven by the fact that I was pregnant, and we wanted to get services in place, so that I would have some kind of relationship with these people before the new baby came. . . Enough of the evaluation had been done. It was sort of complicated, but we appealed directly to the regional director, and we were told the key things to say.

S: Do you recall what some of those things were?

L: That Eli was a child who had normal development and suddenly regressed; that the longer he has this condition, the more intractable we expect it to be; that we're a family with another baby on the way, and we need to get these interventions underway -- that these were sort of emergency conditions. And that worked. But, the services that we got were not yet ABA. We did sort of a mix of OT, speech and special ed. Over the course of the summer, we kind of broke into that and got comfortable with those providers. But after a couple of months, the speech therapist started saying, "You know, I'm getting a lot of resistence from this kid that I see sometimes and don't see other times. When I see this, kids who also get ABA seem to really benefit – I can be more effective when that is also going on."

S: Is this the first you had heard of ABA?

L: Yes, I think really the first time I heard about it was from this first speech therapist that we had. She kept saying that, but we were so overwhelmed and not really settled in even with the idea of having therapists coming into our home. I think that we had a periodic team meeting, and a couple of different therapists talked about what they were feeling they couldn't accomplish right then. The social worker recommended that we make an appointment for a second-opinion diagnosis with a developmental pediatrician. The thinking was that we had gotten this sort of "like- PDD" but not PDD diagnosis from the evaluation agency, and that if we really wanted to go back to EI and ask for ABA services, we were going to need a stronger diagnosis. . . . We made an appointment with Dr. M, and I believe that she gave Eli a PDD-NOS diagnosis at that point. We were left with the impression that that was required, and was the unspoken guideline for having ABA services from the city.

At this point I'm so much further along the road of knowing exactly how EI works. I've gone to meetings, I personally know several of the regional directors who make the substantive decisions about what kinds of services kids should be getting, matched up with their clinical support. It's not necessarily true that you have to have that diagnosis, but then it may have been true in the fall of 1998. It's certainly not now.

S: So you're saying that currently children would not need to have that [PDD NOS] diagnosis to get ABA?

L: At the EI level, with or without that diagnosis, a kid who has delays across the three domains – communication, socialization, and physical -- that meets the federal EI guidelines, if the parents say they want ABA, they'll probably get it. It's not at all clear to me that you need to have an extensive outsider evaluation anymore. I think that's partly because folks within the city system started saying, "We're beginning to notice a pattern of who gets these outside evaluations – it's the people who can pay for them." There are plenty of other kids who still need equal or greater, but they're just not getting those evaluations. I think the clinical base in the region of people who are qualified do the diagnosis has grown slightly as well in the last five years. So there are some other variables. Maybe it's less difficult to get to a provider who will do that [ABA], because there are some more. I think that the agencies that contract with EI are also much more pro-active, because they really do understand that kids who get robust adequate services early are the kids that they can really point to as their success stories.

So, Eli didn't start having ABA until maybe October of 1998. He was real resistant to it for a long time. There were a lot of tears and a lot of tantrums, a lot of difficulty with the really basic mythical ABA tasks like dropping the block in the bucket.

S: And where was Eli receiving his ABA?

L: That was done in our home. I think we started with relatively few hours -- 10 or 12 hours a week – and we built up to the mid-20's at the peak.. We were never doing the 40 hour week intensive program, partly because Eli still napped. I'm really not sure how a child under 3 can do 40 hours. There's just not enough stamina there. Although, by the same token I'll say that the ABA that he was getting, although it was lots of learning, very reinforcer-based, very contingent, teacher-response, was not as mechanical as what mythically I seem to encounter among people who have seen a little bit of film or who have read about it but never seen it. Some of our providers who started out with Eli are still working with him, and the manner in which they deal with him is very loving and affectionate. I think that's very important, because he is a very praise-motivated kid today. He will work a long time for just social praise. He'll work a long time just to fill up his token board. . . . And I think that's great.

S: And so your overall assessment of that Early Intervention period would be?

L: I feel like it was a very positive experience overall because your provider agency has a kind of paternalistic role for you. Because the federal law provisions for it, they're interested in parent training and parent support. They have some capacity to hook you up with other parents, and help you network if that's what you're interested in.

S: Is that something you did at that time?

L: Yes. Several families came when they were at the very beginning of making decisions, and watched our kids doing ABA, to see if it was something they would want to try or not. And, I met parents informally. There were YAI conferences and parties. . . . [Talks more about YAI] When you transition to CPSE, most agencies seem to have somebody who guides you through the transition.

S: How did that [CPSE] transition work for you?

L: Our service coordinator started on us very early: "You need to go look at programs.

You need to think about what you're going to do when Eli turns 3." At the time that Eli turned 3, going straight to SEIT at home and basically continuing your same EI services wasn't something that many people were doing. There seemed to be a fairly strong sentiment that Eli would benefit from being in a school setting. And so we looked at preschools, and we went to SE Preschool #1. And, they did ABA, or at least they said they did, but they did it very differently. Most importantly, they used the same kinds of contingencies and reinforcement techniques and many of the same instructional techniques, but their curriculum was very much more "one book for every kid." I struggled with them for a long time during that year over questions like. . . . [describes an instance where the school was unwilling to alter its approach to a specific task – even though Eli was much more successful with his home program's approach to that task]

S: What was your feeling about the interaction with them?

L: My feeling was that, for behavior management in the classroom and for the presentation of the instruction, they were doing the right things. But, they were missing the last cornerstone -- and I'm coming to the view of thinking it's the most important one -- that you have to alter the curriculum based on the kid's performance. You have to deal with motivation, you have to deal with data, you have to deal with reinforcement, and then what you're actually teaching them has to be what they're ready to learn. They just didn't seem to want to tamper with that. And it wasn't just cheapness over materials. I actually think it was a staff and training issue where the classroom teachers usually have a masters or are in progress with a masters, but the teaching assistants at the preschool level (and I know in the Department of Education), if they have an associates degree that is fabulous, and if they have a GED, then that's adequate for them to be there. And depending on the internal training of the school, that can be better or worse. I think this school wasn't very willing to alter its instruction because that would be overwhelming for the staff. They did a lot of switching around which kid the teachers were working with so that there would be generalization. That makes sense at a certain level, but it also means that every teacher has a learning a curve of dealing with every kid. So, there's a lot of teacher learning happening in that classroom, and maybe not so much student learning happening.

S: How long was Eli at that school?

L: He was at that school for a year, and then we went back to home programming and sent him to a local preschool, sometimes with a shadow, and did ABA at home.

S: Was that something you had to negotiate through the CPSE?

L: They seemed to be okay with that because there's a shortage of center-based spots. So, if you'll opt out of a center-based spot, they're usually okay with that. Unless you require more than 35 hours of service a week, I think they're ahead of where they would be with center-based program and transportation. I don't know that it's all about numbers with them, but they sure act like it's all about numbers. So, we did that for a year.

S: What was that like for Eli?

L: For Eli the time spent in the local preschool was not really very beneficial. There were too many kids. It was not structured enough for him to really gain a lot of benefit, and he spent a lot of time going to a quiet book area and being away from where the other kids were. It was only at the very end of the year that he was able to sit with the other kids during circle time.

S: How about home services during this year?

L: Oh yes. He was getting something right under 30 hours a week of services – maybe 12 of that was SEIT or shadow at preschool, and the remainder was ABA at home, or speech. And he had some OT at a clinic down here in the neighborhood. And we tried a lot of other things that year. We did some auditory integration training. I can't tell you if he actually benefitted from those things – I think his listening got a little better. . . . [a little more on this topic].

In the fall of 2001, Eli started at D75 #1 in kindergarten. . . . And so for 2 years Eli went to D75 #1 in a 6 to 1 to 1 ratio classroom – 6 students to 1 teacher to 1 aide.

S: And the other children in his class, did they have similar diagnoses?

L: Yes. As we were doing our turning 5 transition, there was a whole lot of talk about how the Department of Education's continuum of services was changing. They quit using the MIS and SI labels, and switched over to ratio, and changed from programs using just one kind of classification to programs where a Downs and a Cerebral Palsy and an Autism kid might theoretically be in the same class. I completely understand this as a matter of efficiency, but as a matter of staff expertise, I really wonder about that. The needs and learning styles of those three kinds of disorders are pretty drastically different, and what is suitable for one is going to be totally unsuitable for another. And, I realize that sounds really silly because, and the same time I'll say that kids with autism are all over the map. You can have six kids with autism who don't belong in the same room at all. . . .. But, it turned out that even though that classification thing is no longer in the regulations, there still is a real ghost of it in practice. And so pretty much the school had autism spectrum disorder kids in it.

S: One other question: Here you're transitioning again – this time from preschool to elementary school. What was that transition like for you?

L: The emotional characteristic of going from EI to CPSE is like out of a warm bath and into cold water. You're on your own, you don't have a service coordinator who is responsible for you. Now, the questions about services are only about the kid, they're not about the family. So, you can feel sort of unguided and alone in that sense. But, when you go to meet with CPSE, you're usually meeting with one person, you don't have to declare a disability. Preschoolers are simply "a preschooler with a disability." So, if you're having confusion or disagreement within your family about what diagnosis to embrace for your kid, you don't have to answer that question at that time. The standards for getting services in EI are a little looser -- it's like "may benefit." But when you get to CPSE, it's "least restrictive" to some extent that's the issue, and also "appropriate." The expectation that I felt from the CPSE administrators was that we would have done a little research. We would have already looked at a couple of schools when we met them.

. . . [Laura talks about meeting with a CPSE administrator to discuss preschool placement – the tape breaks at this point and 15 to 20 seconds are lost]

We had a lot of pre-discussion [with the EI team] about "Was this suitable?" "Was that suitable?" "What kind of program did they run?" "What was this like?" "What have you heard from other parents?" There was a lot of opportunity for research and a lot of expectation from CPSE that we were going to come having done some research. We ended up arguing with the CPSE officer over whether Eli needed home programing in addition. We eventually decided not to go to a hearing on that, and just pay for it ourselves.

S: So you paid for Eli's home services?

L: Yes, during the preschool period we picked up the tab for that. But when it came time for John [her younger son with autism] to be a preschooler, we asked for a dual program and we got it. That's partly because of political change that was happening on the other side of the table, and not necessarily because of us.

S: Why do you think that was the case?

L: There was a greater willingness to do that because other families had gone to hearings and prevailed. That was our understanding at the time.

So, we disagreed with the CPSE officer about that [receiving home services], but she agreed with our recommendation – that was when we went to SE Preschool #1 for that year. When we came back the next year, we said, "We're not so happy with this. This is what we want to do instead," and she was all too happy to approve that. It was probably less money, and we felt we would probably be getting better services. And, in some respects we did get better services, although we got less value out of being in the preschool setting than I had thought we would.

When it comes time to transition to 5, that becomes much more intimidating because your capacity to get information about the options is -- well certainly in late 2000 and the spring of 2001 when I was looking -- nothing. There's no list. There's no publication. The best source of information that I found was looking in the blue pages and finding the listings of the schools. I actually ended up calling schools – which must have been really annoying to the staff. I called District 75, and got bounced among no less than six people -- never got answers, never got material. I got some useful sources locally by talking to my neighbors. . . . But that's an extraordinary way to get information. That's totally outside the institutional structure.

S: So there was nothing within the institutional structure that helped you make these decisions?

L: Not a bit. We simply got the letter with the "sign this consent for the evaluation of your child for transition, agree to have him observed, and get your own private evaluation if you wish," which we did. I had phone and paper communication with the person who was the "turning 5 coordinator," but that person was not a decision maker at all. The only time you would get to be making a decision would be when you would meet with the committee. And when you meet with the committee, you're only talking about services, not placement. So, we'd be saying, "we think he needs a lot of speech, and he needs to be in this ratio of classroom." You do or do not come to agreement with the committee about those questions, and then you get referred to placement. We got referred to placement – it must have been the middle of May – and I'm flipping out by this point...

S: And Eli would be starting his placement in –

L: In September. Now fortunately, by other means, I found two schools that I thought would be suitable. But, they were totally through social networks and by making a lot of calls. I visited D75 #1 because [a friend] told me her son went there. I felt really good about D75 #1 because one of the teachers there had been a special instructor for Eli when he was in Early Intervention. There was a personal connection there. I looked at that school – they're very explicit. They have a psycho-developmental model. They want to get kids not to work for reinforcement. They want kids to learn for the sake of learning, they want lots of social praise. They're behavioral in terms of the classroom management, but they're not behavioral in terms of instruction.

And I looked at another school . . . I think they were called D75 #2. . . . I got to observe a kindergarten class where they were rolling in ABA classes. . . . And my understanding in talking with the site supervisor and the assistant principal there was that offering ABA instruction within the Department of Education was something that District 75 was doing in response to parent pressure. . . . The home provider who went on the visit with me and I were underwhelmed with what they were doing in the classroom. We saw some examples of both the classroom teacher and the teaching assistants responding to problem behavior in ineffective ways. It just seemed very much like a work in progress, and it had a long way to go before it was a smoothly operating program. . . . They also had lousy space. They had no OT room. A lot of times when District 75 programs are housed in other schools they get the lousiest space. . . . I just was completely not sold that they were going to really invest in this, and that the people from [an ABA training program] were there often enough or long enough in the pre-service period that the staff had really any clear idea of what they were doing. And so I said, "Okay, I would rather be in a school that is institutionally stable and has relatively low staff turnover -- all those things that I think are usually good signs of a healthy school -- that doesn't do what I think Eli benefits most from pedagogically, than one that *might* be doing that but seems to have too many balls in the air. I'd rather have no ABA than possibly very bad ABA. It may not be very effective instruction for him but it probably won't be doing him any harm or conflicting with what he is accomplishing at home.

S: And so your plan was to continue ABA at home at any rate?

L: Yes. [Talks a bit about ABA program at home] So, that was my logic for deciding between those two schools. I was not allowed to know who the placement officer was. I asked several times, "Can I talk to the placement officer?" "No, not until you've had your committee meeting."

S: What do you make of that?

L: It's just not a consumer-driven process at all. I was furious. I would have said, "I don't know about the outcome of my committee meeting yet, but I think that we'll be talking about these ratios, and here's Elis' category. What [schools] should I go look at so that I will come to the meeting informed?" No, no, that's not how they wanted to do it. It was definitely services first. [They must have thought] you'd be arguing for services on the basis of the school that you wanted, or something like that. But smart people are going to do that anyway.

Having made my decision between D75 #1 and D75 #2, when it was time to go to placement, I said, "By the way, I really like D75 #1. If you pick D75 #1 for me, you won't have any more problems from me." And I was very frank about that at that point, because I had gotten kind of savvy about how they work and how they don't work. A week later the letter with the recommendation comes in the mail and it's D75 #1. I'm like, "Okay, we're done." And my understanding from other people who had transitioned before was, "When you get the letter, go visit the school immediately. If it's not suitable, then you need to start making noise right away, and you need to have criteria that you think the program doesn't meet." I knew some other people who had gone through those steps. For them the target that they had in mind was to get a non-public school.

So that's basically the pattern that we followed this past spring as John was transitioning to 5. We said at the outset, "you don't have a program that is suitable for this kid. He needs non-public school." Amazingly, we got it on the first committee meeting.

S: That does sound amazing.

L: My personal opinion is that our meeting was the last week in May and a lot of those people who sit on those committees, they got fired at the end of May. And even if they had continuous employment, they had to reapply for their old jobs under the reorganization. Out of a fluke of scheduling our committee meeting for each of the boys was on the same morning, two hours apart, with two different committees in the same building. We met with the first one, for Eli. Teachers from his school and home programmers and us. His second year at the school I had constant complaints and they were sort of tired of me, and had finally come to the place of "maybe it's better for him to be somewhere else."... [More about why she didn't feel program worked for son]. I think that they finally got comfortable with that. So this was not a rancorous meeting. We had pre-argued it with the District 2 psychiatrist that Eli had been evaluated by. We had a big paper record of the stuff we hadn't been happy with – which wasn't malfeasance on anyone's part. It was just not a good fit, not working for Eli.

[More about characteristics of this specific school]. They are unique. . . it is theoretically possible they can have a kid from 3 to 21. And in an age where we seemed to be crazed with accountability, a program that actually has a kid from 3 to 21 . . . [those kids] are really theirs. Whereas in many other parts of our present Special Ed system, nobody has any accountability because you're only where you are for three years. When we first transitioned Eli into CPSE and we were arguing with a woman about the home ABA component and we were saying, "Look if he has enough services, he may actually get better." I said to her, "You know, Eli will graduate from the New York City Public School System in 2016, so you guys have got him for awhile." And she said, "No, I'm only responsible for two years." And I wanted to smack her. I'm like, that's not the point. Yes, I understand that institutionally your little accountability frame is only that, but you're part of a bigger system and it is responsible for him. And it's not doing a very good job if that's how you all think of it. And that's how most of the system thinks, because that's the way it's cut up into little segments. . . . [Some conversation about the school system reorganization]

S: So then in May you met in the morning with Eli's committee —

L: Yes we met in the morning with Eli's committee. And we had pre-argued and my husband had called the committee chairperson because their name was on some paper work. We had really softened them up ahead of time, so they were saying non-public school. One of them, I think it was the regular education teacher, at the end of it she said, "You know, this doesn't happen very often. You've got to really appreciate how unusual this is." And my husband and I are looking at each other – "Does she know we have another meeting in an hour?"

So an hour later we go back upstairs and meet with the second committee. And the regular education teacher from the first committee is on this one. . . . And then we had even more people for that because John's school sent the service coordinator, the educational director and the classroom teacher. Between the two boys, John is a much bigger management problem. They talked about that he is assaultive, they talked about his sensitivity to noise, they talked about a lot of things that make him a little bit more challenging. . . . It seemed to be awfully easy to persuade them. And at the end of that, the regular ed teacher said to me, "So you have two?" Yah, no joke.

And we weren't sure from week to week if we would have a spot at this NSP#1, because they had an application pending with the State Department of Education to open a new classroom. If they got the new classroom, they had room for us, and if they didn't, they didn't.

So that was around the 22nd of May that we had these meetings. Then we had to wait for – it felt like 10 or 12 weeks.

S: And if this hadn't have worked, then?

L: We were completely – well Eli was going to D75 #1 school again. And I don't know what I would have done with John. . . .

S: This was your one good option then.

L: Yes, really the one. But I think those meetings were as simple as they were because those people had pink slips. I really honestly do. I reported to different people, and I now know a handful of people who are either contractors or somewhere in the Department of Education system, and they say, "That's astounding. That's unheard of. I can't believe that". . . .

S: Will you have to go through this all again at the end of the year?

L: Now that we're in a non-public school program, they [the school] will be with us when we go back for whatever the follow-up meetings are. I think that the annual review is pretty perfunctory, but the triennial is more thorough. I think. Now there's a lot of nervousness among parents that I talk to about what the re-authorization is going to be like and whether you will have to have new goals every year. The upside of that is you might not have to go to a district office every year and have a not-very-meaningful conversation. The downside would be that there would be nobody from above saying, "you have to have new goals every year." . . .

> [Laura talks a little more about the re-authorization. She then talks more extensively about her experiences and frustrations with D75 #1.]

And then there were some issues over – Eli developed a behavior problem in class. He did some biting. They were less open to doing a functional behavioral assessment of what's leading to this, and more concerned that if a staff member gets bitten they have to leave the school and go seek medical attention – it's a union rule. Not that I'm not sympathetic to the person who gets bit, but sometimes that [going to the doctor] is not absolutely necessary. In his kindergarten year I spent a lot of time at the school, so I got to observe a lot a stuff more closely . . . I started to see that there were a lot of things in the culture of the school that were about what somebody else's rules were and not about . . . what works best for the children. So, for example, the classroom teachers never lunch with the children. It's in their union contract that there's no instructional lunch. And I'm thinking, you know for these kids it's such a tremendous opportunity, and you're passing it by. There are a lot of other ways to handle that. . . .

I really came out of that two years feeling like there are some really good people there, but they're operating under rules that impair their natural ability to do a good job, that control and count things that don't matter so much, and don't control and count things that do matter a lot. And so there's a level at which I'm just really happy to be out of that system. . . .

In our second year when Eli began to have some problem behaviors in the classroom and he bit a couple of peers (fortunately without injuring them severely) and he bit all three of the classroom staff that worked with him, we got him a one-to-one para. Actually, I think that was why Eli's May committee meeting was relatively easy: We had been there in November saying "we want a non-public school. This is not working." And they said, "well lets exhaust what we can do. Lets have a one-to-one first and see if that improves things." And by mid-February we knew that while the one-to-one was helping, it was not doing enough. And so, when we came back [to the committee] we were a familiar file. We were a familiar case and they knew that we had already taken those extra steps. I think that made a big difference.

S: It strikes me that you are a really savvy parent. How does someone get to that point?

L: I think that having two kids made a big difference. The fact that I'm a person with a policy orientation to the world anyway, and I can see what values institutions are expressing and not fostering. I have a pretty effective framework for perceiving what is going on. And, I talk to a lot of people. I find people who did this before, and say, "So how did that go?" With a friend in the neighborhood, I started a parent support group. We don't do anything in the way of any kind of social work in the context of these meetings, but I keep the names and send out the flyers and do the basic administrative piece of that. . . .

So, one piece is that I'm something of a natural networker, and the other piece is that I have, both from schooling and from natural inclination, a framework for understanding what these institutions are doing, and have a framework for separating the people at D75 #1, who I like and I think did take mostly very good care of my child. But the system in which they function is profoundly undermining their effectiveness. And, at the same time I saw when we went for the meeting in November of last year and ended up getting the one-to-one, that a lot of the pressure they were feeling and the tension we would have when we had parent-teacher conferences was -- Well finally, in February or March of last year, we had what I thought was a break-through conversation, where they were saying, "You know you keep on about this, and we as a school, if we can't hold on to our purpose and our methods then all these other kids are going to suffer." I'm like, "You know I'm not responsible for all these other kids. I'm supposed to be responsible for my one kid, and it's not working for my one kid. And if you just would let us out — the next time we go to a committee meeting and I say it's not working, if you would just back me up there, I will be out of your hair and out of here and God speed." And I think that if I were an administrator of a far-flung program with six different sights and were facing the Children First reform package, with a new mayor and a new chancellor, I'd be freaking out. What they've got, they believe in and they think it's working. And, it's very fragile. They could be minced up into little tiny pieces and thrown to the wind. And it would be terrible for the kids, because continuity – even continuity of imperfection is better than being shaken up and all over the landscape. I would like them to nudge over to being more behavioral. . . . but I'm not in that school now, so that's not my problem.

S: I have a couple of global questions for you. If you were invited to give your input to the whole Special Ed system, what would you say is needed?

L: I think transparency would be the thing I would really, really push. For regular ed kids there is a limited amount of choice and it's structured, but its rules are clear. Some parts of it are dictated by lottery. . . . other parts are dictated by complicated composition formulas, but they're also transparent. . . . What's available on the special ed side is really, really not transparent. My first experience of transition was, "well we can't tell you." The District 75 people didn't have a list of their own programs and the constituents in them. I just thought that was extremely improbable that they didn't have a catalogue of their own offerings somewhere, somehow. How could you plan and operate your system if you don't have that?

The transition to CPSE is completely different in that respect. They send you a book. It tells you about the specializations and characteristics and staffing patterns of the places. A lot of times there are four flavors, and this one offers two flavors, and this one offers just one, and that one offers something else – because the flavors are dictated by the ratios that CPSE will reimburse. That's fine. If what you have has rigid building blocks, that's fine. Just tell me where you have it, how many spaces there are, who I can talk to, when there might be open houses.

Also, I think moving the meeting and placement process a little earlier in the year would certainly help out. When we've been in situations where we might be in a public program in the fall or we might not, all the other families you encounter, normal and not, they know where their kid is going to go in February.

S: What do you think would be the best timing for those meetings?

L: I think that the younger the child is, the more you run up against the problem of "this child might change drastically in the next three months, and we're not even measuring the spring semester as we make this decision." But I think that when you're transitioning into school that's really, really less of a factor, particularly if you're a kid who has been getting services for awhile and this is not your first encounter with being in the special education framework. We had a situation with the preschool down the block when we thought John might be going there, but we weren't sure. Well, we put a deposit down for the fall, because you have to do that in February, and if you don't you probably won't have a space in the fall. We ended up kissing some of that deposit good-bye because I didn't know and didn't know until the middle of June that John was going to go to this other program. . . .

The spring when Eli was turning 5 and this spring when John was turning 5, those were really tense times, because there was a lot of waiting and uncertainty. For us the uncertainty this summer stretched through the summer because of the business with the classroom at NPS #1, but I knew that came from somewhere else entirely. But the *spring* uncertainty is totally the school district's problem. It could be managed quite differently, and much more transparently.

I realize that individual programs within District 75, as well as the inclusion programs and team-taught collaborative programs – I think especially the ones that are new, are very sensitive about that kind of thing. If they're going to be listed in a catalogue, what's it going to say about them besides their ratios, their input, their available services? What's it going to say about their performance? It is very difficult to find performance figures that are meaningful at all or comparable at all in very different settings. But even the most rudimentary level of catalogue of what is available, programs and ratios, and maybe some aggregate data about what kinds of kids are in those classrooms this year, that would be a tremendous help. And, it would also help other people look at the system – it would create the basis for a more effective public conversation. . . .

S: One last question, if you were talking with a parent who was just coming into this process, what would you say?

L: I would say, network with other parents. Try to meet people who have been in your shoes, who've walked down that road. Appreciate that a lot of what is available is available because of these other people who've been down the road before you. Before IDEA things were not so great. You're going to benefit from the fighting that people have had to do. Just to be physically present in the school, to have inclusion if that's suitable, to have non-public school if that's suitable, to have an individualized and appropriate education. If your kid meets those criteria and she or he is over in the not-regular-ed pool, then they're supposed to get an individualized determination. So, talk to and network with parents, and even though the new language of the Department of Education is this "continuum," and it suggests that there are many, many points on the continuum that would accommodate many, many different individuals, it really only has relatively few categories. Don't forget that your child is supposed to get an *individualized* and *appropriate* program. If the program is not appropriate or not individualized, then it's not right. That's a federal entitlement.

Email correspondence with Parent A ("Laura"). Monday, November 24, 2003

As I've gone over your transcript, a few questions have come up:

1. You mentioned that Eli began to get ABA therapy in October of 1998. You said he started with 10 hours a week and built up to the mid-20's at the peak. Were other therapies (Speech, OT, PT) included in those hours, or were they extra?

    Eli has never gotten PT. OT and speech were in addition to the hours I discussed, usually 3-4 of OT and 4-5 of speech.

2. It sounds like you worked with YAI during the Early Intervention period. Did they supply your therapists and service coordinator? (If not, where did you get your therapists at that time)?

    Yes, except for private services (and schools), YAI has always been our agency. We got service coordination from them in EI for both boys.

3. My understanding is that while Eli was at SE Preschool #1, you were paying for his home services. Is that correct?

    Yes, 10-12 hours a week. We heard in that year that a few families had gotten center-based preschool plus home programming approved as the outcome of a hearing, but we were uncertain we could show a regression and chose to self-fund for that year.

4. During Eli's second year in CPSE (while he was at the local preschool) were you paying for home services? What financial support did CPSE give at that time other than funding Eli's SEIT?

    In Eli's Pre-K year, we paid the preschool and CPSE funded a total of about 30 hours weekly of services, which were split between SEIT at the preschool at home therapy.

5. You mentioned that at the time of your EI to CPSE transition, you were given a book that had some information about the different preschools. Who gave you this?

    Our service coordinator at YAI (or the transition specialist there) gave us this document, but I believe it was prepared by CPSE itself.

Transcript of Interview with Parent B -- "Denise"

"Anna" - 9-years-old

This interview took place in a diner on Staten Island on October 21, 2003

[First 35 seconds of tape inadvertently erased. Denise was explaining that she has 2 children: a 9-year-old autistic daughter Anna, and 6-year-old typically-developing son. She said that her son has always had a special, helpful way with his sister. To illustrate, Denise told about a time when she was trying to toilet train Anna].

D: . . and I was in my little bathroom downstairs with her, sitting on the stool – you know I had to be in the bathroom every ten minutes trying to see if she would be successful – and doing maintenance with her, doing the flash cards. "What is that? What is this?" And the phone rings. I set my things down and I went to go get the phone. I come back and her brother is doing this work [the flash cards] with her. It was so cute – he really knows what he is doing.

So that's the whole family. And with the Grace Foundations . . . everything we do includes the siblings. We have a little league where the siblings can play, we have bowling – all our recreational programs. And we also offer sibling support groups, because they're so affected. I truly believe that if the mother or father are in denial or don't get trained on how to teach their children, they will not do well. So, it's so important that the family is involved with the education. I myself got trained when she was two, in ABA.

S: When was your daughter first diagnosed?

D: She was diagnosed at two. She didn't speak. So we took her to a neurologist, thinking she'll need some speech therapy. I knew nothing about autism.

S: Had you been concerned about anything else up until that time?

D: No. I had no idea. She was my first child. I had no clue. If she were my second child I probably would have known. But no, my first child – I had no idea.

S: So you went to the neurologist and what happened then?

D: I was referred to Early Intervention. And they had an agency that sent speech, OT, and a special ed teacher to my house. In those days I got 15 hours total – 5 hours speech, 5 hours OT and 5 hours special ed.

S: And the special ed was?

D: Well the special ed teacher is the one she responded mostly to, and I think it was because she was using ABA.

S: What was Anna's diagnosis at that time?

D: PDD, possible PDD-NOS. PDD is autism. Now her diagnosis is just PDD, and I tell everybody that she's autistic, because that's what it is. It's just a nicer word, but that's all it is. So, the special ed teacher was using ABA and I didn't know it. At the same time I was going around to different conferences and reading, and I read about ABA. I was like, "Wow, this is the only proven method." So I asked the special ed teacher, "What method are you using?" She said, "ABA." I said, "Are you kidding me?" Because I could see with my own eyes that Anna was responding the best to this one particular teacher.

S: And that was only 5 hours a week.

D: Right. So then I hired a whole team privately.

S: You had to pay for it?

D: As ever.

S: What happened with Early Intervention? Did you petition them for more support?

D: Yes. They said, "no."

S: And what year was this?

D: 1996. So, in today's day and age, you would have gotten it. Today our problem is after five.

S: I'd like to hear about that. To get us there can you talk about what happened when Anna transitioned into CPSE.

D: Anna went to SE Preschool #2, an ABA school, for 5 hours a day. And then, after school I did private ABA two to three hours more a day.

S: Was her preschool funded?

D: Uh huh, yes.

S: And how did that process go?

D: They gave me center-based, but they refused to give me the after hours of ABA. So I continued to pay on my own, and I sued the Board of Ed and won 100%. It took me about two years to get my money back, but I did get it. I was the first one on Staten Island to get it actually.

S: Can you tell me a little more about the process?

D: As soon as she started preschool we sent a letter saying, "this is inappropriate." I lost my first impartial. I went with just my husband. And then after I lost, I went to another attorney, and they told me, "you go back." And we went back and we won.

S: Were you receiving any encouragement or support at all from the people who had worked with you in EI or --

D: No. The people in EI didn't believe in ABA at the time. That particular agency still doesn't strongly believe in it. ABA is tough because your teachers are accountable.

S: Can you explain that.

D: Everything they do is written down in data. Charting and data is done every day, with every little thing they teach. So, there is a lot of accountability there. And it's important to have that accountability, not just so they can look and see what you are doing or for your superiors, but to see where the problem lies – so your team leader/teacher can make adjustments and fix what is wrong.

S: During this preschool time, what was your interaction with the CPSE?

D: I was happy with the preschool. The special ed committee is one person. You know, they claim their hands are tied, that's all they ever claim. "It's not my job," or "you're asking for more than we can give you," and "you have to go higher, so you have to go to impartial." They don't encourage you at all. Most of them know you are absolutely right, but because it's their job nobody really takes a stance and advocates for you. Not at all.

S: So you got your reimbursement after two years –

D: I won and then it took about two years to get a check. But I did win 100% though. And they give you a lot of aggravation too. I had to show every check. So in other words, Martha worked with Anna two hours on March 1st, and this is the check that we paid her, front and back. So it was a whole bookkeeping system. Quite frankly, most parents don't do this because they're overwhelmed. Living with an autistic kid alone is overwhelming. To add this to it is simply ridiculous. But I was just determined.

S: That's interesting. I spoke with a parent of a younger child the other day, and she said, things are so much better now because of parents like you who went through the lawsuits.

D: Absolutely. My case study is definitely used. And the same thing with Early Intervention. During Early Intervention I never fought for anything. I didn't know. I took what they gave me and paid out for the rest. But, by the 3 to 5 program, I went after them.

S: And what motivated you to do that? Were there other parents?

D: No, none of my friends at the time did that. People thought I was crazy doing the amount of therapy I did for my daughter. But if you see her today, it was worth it. I mean her behavior is beautiful. But there are many reasons why she is doing well now. A lot of it is Early Intervention, and really I'm not unhappy with Early Intervention or the 3 to 5. Our problem is after 5.

S: Okay. Tell me about that.

D: After 5, you're offered Board of Ed programs usually. There are very few programs for autistic children after 5 years-old.

S: And were you given any information about those programs?

D: No. The committee makes a recommendation but you're not allowed to see it. They come in – the Board of Ed comes in and evaluates your kid. It's not a long evaluation at all. These kids are usually untestable because they do not do well in strange places. My kid was asked to go to the CSE. They do not do well with strangers and they don't do well in large environments. You cannot go see any of the programs until the committee makes a recommendation which is not until school almost opens. So, the whole process stinks. But the bottom line is they don't want you to decide where the kid is going. And once they make a recommendation, such as like a SI III program in those days, they don't tell you which SI III program you've been assigned to. So you don't even know the building or environment, nor do you meet the teacher. Another problem the Board of Ed has: there is no open door policy to any of their programs.

S: Meaning that you're not invited to visit?

D: You're not invited to visit unannounced or without an appointment.

S: Is that still the case, as far as you understand?

D: Yes. I have a very large problem with that. When you have a non-verbal child – I'm not saying you have to be there – my daughter's school right now has an open-door policy. She goes to a private school. I never go there, but just knowing I could is a big thing.

S: I'm sure it is. So your daughter went through the evaluation, you went to the committee meeting and they said –

D: They recommended a program for her with only autistic children. They did not offer me a private placement such as [names two private schools]. They offered me a SI III program, as it was called at the time, a 6 to 1 to 1 in D75 #3 on Staten Island, which has no opportunities for inclusion.

S: Is this a District 75 school?

D: Yes, it's a District 75 school. At the time, my daughter could speak. She could get her wants and needs known. She was toilet trained. She was ready for kindergarten. She knew all her shapes, letters, and all the beginning skills. My biggest problem was that no inclusion was offered to her. There was another inclusion program at D75 #4, where I wanted her to go.

S: And that was a public school?

D: Yes, that's a public school. But when I went to see it, even though it wasn't offered to me, the site was too overwhelming. The buildings are huge and the school is huge. . . . [Specific identifying information about the school]. They had three little SI III programs in the basement, but they'd go to the lunchroom with 200 kids, and had to walk through huge buildings to get there. It was totally inappropriate. Nobody in Board of Ed realizes this; nobody cares to realize this; nobody understands this. Everything is about environment with these children. Environment, environment, environment. That's why I feel that none of our kids could do well in a Board of Ed setting. Yes, some people claim they're happy, but they don't understand. If they had their kid in the proper environment with the proper support, how well they could really be doing. And, in a lunch room with 200 or 300 kids, or 100 kids or even 20 kids, it's too much for these kids. And a gym that is overwhelming is too big for these kids.

So neither site was appropriate. So what I did was, I put her in a private school . . . and she goes with a private shadow.

S: Is this at your own cost?

D: All at my own cost. I sued the Board of Ed for reimbursement. They're behind 2-1/2 years, and I do not get full payment. I settled for about half. It costs me over $30,000 a year to school my daughter. She gets a 1 to 1 para, I pay her tuition, and after school every day she gets two hours of ABA tutoring.

S: Tell me about her class.

D: The class size is about 15, but they break up into two different groups. This particular school groups the grades together, 1st and 2nd together. So they break up in two small groups to work, and they are set up in a Montessori-style classroom where there are manipulatives on the shelves to work with. So they work on their own, one-on-one, after a lesson is presented. They do not have to sit at a desk with their hands folded for any long amount of time, and between each work period are sensory breaks. There's a whole sensory area set up at the school. When a child gets overwhelmed by the environment in any way, they go and there is a trampoline, there's a swing, there's equipment that can calm them down so that they are able to get back to their work an focus.

S: What's the make-up of her class in terms of the other students?

D: They're all typical children. Anna's behavior is beautiful. I have my lead teacher in there once a week asking the teacher if there are any problems with her. And when there is a behavior, it is taken care of immediately. For example, one day last year -- they go to red line in the morning -- and on red line my daughter was screaming. The teacher had the para remove her from the line. So she was being rewarded for her bad behavior. My team leader, behavior specialist, came in and told the teacher very nicely, "you have just rewarded her bad behavior. She cannot get removed from the line until she *stops* screaming." So, my behavior specialist is forever teaching the teacher how to deal with Anna, and her behavior is beautiful today.

S: Tell me about your behavior specialist.

D: This is someone who has been with my daughter since she was 2. . . . She oversees my team at home, and the staff at school. She has trained my paras in ABA, and my team at home. She picks the programs we will be teaching and she meets with the classroom teacher, who is not employed by me, on a regular basis. Along with me, she finds out what they're learning in school. We find out what they're going to teach in science. We know with math and reading -- we have books to figure out what they're going to teach first. But with social studies and science, we find out what they will be learning, and we teach it before Anna is presented the material in the classroom. So she learns a task, she learns her work on a one-to-one basis in a quiet setting in her room at home, through ABA. And then she generalizes what she has learned in the classroom.

S: Wow.

D: It is wow. This is what the Board of Ed should be doing for every child. And I have a big problem with the Board of Ed because they refuse to implement any of this. And to top it all off, I looked up one year how much it costs for a student at D75 #3 to be schooled at the school, and it was $60,000. Now that includes bussing, which I don't get. Well for my daughter, it is half the amount of money. And when I sue them for reimbursement they don't want to give me any money. I settle for much less. So I think it is a damn shame that they don't understand this. It's all about environment. Our schools are too big. What the Board of Ed needs to do is to contract out little, little buildings, small structures, and house these children. . . . They need to open little sites. These buildings alone are too large and overwhelming.

But inclusion is very important too. I think my daughter's behavior is good because of her inclusion program. She has wonderful peers around that do not have behaviors, so she does not know bad behavior.

S: It sounds like you are giving your daughter a wonderful experience.

D: And it's a lot of work and a lot of money. My husband is a police officer. . . . But when Anna aged out and I went to see the Board of Ed's so-called ABA program, it was a joke. You know, I'm not the typical parent – I am trained in it. So when they're showing me an ABA program I know what's right and wrong. I know what discrete trial is, I know about how many programs they should be doing. In the books I did get my hands on, the kids were doing like four programs a week. My daughter did thirty programs a week. This is ridiculous. They say they are doing one-on-one ABA, but the class ratio didn't make sense. It was physically impossible to do what they said they were doing. I wasn't willing to let my daughter regress and try out a program that I knew they weren't doing properly. I had a big problem with that.

S: In terms of on-going meetings with the Department of Education, are they having yearly –

D: Every year they torture my life. Every year they retest my daughter. Three or four different professionals have to meet with her a couple of hours, test her. And the funny thing is that everyone who tests her, on their reports writes, "This child's educational and social and emotional program is up to par, is acceptable, has helped her reach her potential." So the evaluators for the Board of Ed definitely agree with what I'm doing. It's hysterical.

S: But the committee gets together and --

D: The committee is very nice people. They obviously, at this point, when they sit down with me, congratulate me on how beautifully she is doing. Her reports look great. But they claim, "we can't help you. You have to take this to a higher level." Because I sue for reimbursement for the whole thing. Plus a lot of our parents right now are getting P3 letters.

S: What are those?

D: P3 is a way of paying a special ed teacher after school to do ABA for your child if they're trained in it. However, that person has to have a special ed degree and cannot work for the Board of Ed. They are few and far in between. So it's very difficult to get. . . . A lot of the parents go to a regular Board of Ed school and then get ABA at home because they know that's truly how their kids will learn. And they get it through a P3, but you can't find teachers to do it. So that's a problem too. The Board of Ed is still trying to find other ways. ABA is hard. Parents don't want to do it and schools don't want to do it. But I'm telling you, it's worth it. It's the only proven method right now. And I'm not saying my daughter doesn't do other things. Right now we go to a special links-to-language program every other Saturday, because I felt the ABA program at this time didn't know how to link the words together and get her to speak spontaneously, teach her mind blindness and stuff like that. So, I found this woman that we've been going to. My daughter is also heavy on sensory. But we've always implemented heavy sensory stuff in between her programs. So I'm not saying "only ABA," but it's the foundation of 90%. That's what it has to be. And a lot of parents don't even want to do it, because it's a commitment on your side. It's hard to find teachers to do it, it's hard work to follow-through with the maintenance, but it has to be done.

S: So in terms of finding teachers to do it, you went to R University. Is that what you would recommend to other parents, or are there any other places you would send parents to find teachers?

D: . . . It is very hard to find to find teachers now, very hard. It is better known now because there are a few schools that offer ABA . But it's hard. The Board of Ed certainly doesn't have any qualified decent ABA programs. The ones on Staten Island I go to visit are not doing it. That D75 #4 site I was considering, that supposedly offers inclusion with ABA, they've never done ABA from day one. They've never sat down and done the discrete trial. . . .

S: If you were in a position of influence in the Department of Ed, what would you change about Special Ed?

D: I think number one is environment. I saw a [indecipherable] this morning and they say, "Environment. Move, move out of New York City. You're killing your children with the noise level, the sounds, the lights that they can actually hear." They need to be in a school where there are no bells, where there are no fire alarms going off, unless absolutely necessary. I'm not saying, "put them in danger," but you need the little school bells to ring to go to their seat or to line up. Voices have to be at a bare minimum. Once the sensory overload is taken care of, the child is going to learn. . . . So the first thing I would do, is I would rent a number of small, quiet locations to have schools in small structures. These children should not be in gyms with other children. It is overwhelming. They should not have to walk from one class to another in large hallways with big people around. It should be a quiet little place where they can learn. And once you give them the proper environment and you combine that with an ABA program that will teach a task step by step, they can learn. It's not that they can't learn. They can learn.

And another important thing is – A lot of people say, "Oh ABA, my kid's too old for it. That doesn't work any more." Then change your lead teacher. ABA works whether they're two or ninety. [If it's not working] you need to find a more creative teacher. . . . Last year my daughter learned her planets. We didn't teach them one at a time. We taught them five at a time. You can't bore the kid either, but we kept at her on it, and we did it in discrete trials, and when she got the first five, we moved on to the next five.

So that's what I would do. I would train the staff properly. The proper supports need to be implemented when putting a child in an inclusion program. And that's number one. Proper environment. Inclusion is a must. These children are not going to learn how to act appropriately if there are no typical peers. The studies are there. All kids, typical or not, do what their peers do. They mimic, they know how to mimic. So you need to put them with typical children, but they need their own individualized educational plan. And it's not hard. I do it and I have no educational background. I come from Wall Street. So, if I can do it, anybody can do it. And if I had money, I'd be even more dangerous.

S: What's your advice to parents of young children, who are just coming into all of this?

D: My advice is to get yourself support. There are groups out there. There's the Grace Foundation on Staten Island. There's [indecipherable] in New Jersey. There's NYFAC in Queens and the New York area. You need to put yourself with other people who are in your situation, and educate yourself. Go to seminars. Learn everything that you can learn, because there's plenty of things out there, and listen to other parents. Out of all of the crazy different therapies out there, I've done more than half of them with my daughter. But what was important to me was that I asked other parents what they thought, and then I also prioritized what to do.

S: And how did you do that?

D: Well, what really helped me was that first teacher — when I saw my daughter was responding best to that one teacher with the ABA, it helped me to go that way. What I'm finding now with a lot of parents is they're getting the ABA, so now they're focusing themselves on a lot of other different things. And I think they're confusing their child. I think what you really have to do at a young age is ABA. When I meet a new parent I tell them, "Listen to me, and listen to me good – ABA." . . .

We have to teach these children how to function in the world. It's a lot of tough love. So, the first thing the parent has to do is learn ABA and develop tough love. And when they see the outcome, it will encourage them to do more.

S: You've mentioned having this person with you since your daughter was young.

D: I was lucky. I meet people who can't keep a teacher. . . .[Speaking of the home therapists] I open my home to these people. I make them feel comfortable. They're part of my family, they're in my house everyday. "Please help yourself to a drink," I buy them nice gifts. I do what I can. I tell them how much I appreciate what they're doing – whether it's this small or that much. So, I 've been lucky. My staff has been with me for a long time.

S: That's wonderful. . . .

D: As smart as I think I am, the heart always gets in the way. So, from day one I hired this person, because she is my professional. So when I go look at a school or a program or before I talk to somebody, I consult her. I know that I'm not the expert in this field. Although at this point I guess I know as much as her – and she has recently said that to me. But, this woman is wonderful. This year when we started school my daughter went into an elementary grade, third grade, and my para was shaken the first day of school. So we had to have a meeting after the first day of school, to calm my staff down. Yes, this is hard for Anna. And yes, she might have to repeat third grade again. And it's okay. And we're going to take this one step at a time. Anything she doesn't know – up until this point we teach a task before she learns it in school. But it has been hard to keep up because now she goes full-day school, and only has two hours [of ABA] at home. Years ago she went to school half-day and we did a lot more home ABA.
Anna has been in an inclusion program since she was five. I kept her back in kindergarten because socially she needed to be back.

S: So she has been in the same private school since age five then?

D: Very important not to change. Very important not to change [indecipherable] and teachers. That's part of the reason why she is doing so well. Her speech teacher and OT, they've been with her a long time. If there is a change, we use social stories.

S: Can you say a little more about that.

D: My daughter has very high anxiety. Social stories are used to prepare a child for something that's going to change. A class trip — we write a book about it . . . [describes this].

One very important factor in this whole educational social-emotional thing that the Board of Ed doesn't get is that the family and home team all have to work together. When she was in that little preschool, I used to go every two weeks and sit with the director: "Okay, what are the programs she's doing here? Oh, she mastered red. Okay we'll work on blue at home, you work on green." You have to be on the same page. You have to know what each other is doing. How can you generalize what they've learned if the parent doesn't know what they've learned? My son was in a kindergarten class in a local public school. The teacher sent home notes about what they learned. And I was able to go over that with him at home. "Oh, you learned these sounds Mark. Let me hear you say them." Special Ed kids don't get that information sent home. A lot of them lose a skill. So it is important what we call maintenance and keeping up with what they have learned. I trained the grandmas to do maintenance with my daughter. It is an around-the-clock school day. But, it's all up to the parents and then the school, not vice-a-versa.

S: Is there anything in the process you've gone through with the Board of Ed that --

D: That I liked? Nothing. There is nothing in the Board of Ed that has ever helped me. I am courteous, and I thank every person who evaluates my daughter, and I thank the CSE for their time, but that's it. This year I said, "Thank you." I left and I go, "I don't know what I'm thanking them for. They've just cost me four grand for my lawyer." No, there is nobody in the Board of Ed who has been helpful. Nobody goes above and beyond. There's no appropriate placement for an autistic child in the whole New York City Board of Ed. And I will be quoted for that. And there will be parents that will tell you, "Oh my program is good." But they don't really know any better. Is that a shame?

[We turned off the recorder briefly while she finished her meal, and I answered some questions about my project. Then we returned to the subject of Anna's education].

D: It costs sixty grand to school my kid at D75 #3. It costs me thirty grand [for her private school], and they refuse to pay me for it. They fight me on it and I never win 100% at this point because I accept. From what I hear: One, the Board of Ed doesn't want to hear they don't have anything appropriate, because once one person wins, it's used as a case study; and secondly, the teacher's unions are so strong. They want to keep their jobs. RSA's for speech and OT: If you work for the Board of Ed, you cannot be an RSA provider.

S: And RSA is?

D: Related Service Agreement. So, if your kid goes to a private school – Catholic, Jewish, whatever – and receives RSA's from the Board of Ed because they're a special kid, you can't find providers. I want that changed. That is ridiculous. If there are not enough providers, then you make provisions for people to be providers. So that's a very big issue. But, teachers unions are strong and, instead of making the Board of Ed bigger, they need to make it smaller. They need to break it down even smaller than it is. I have to talk to the mayor [laughs]. That's next on my list. So, I have not seen a program that I'm really happy with in the Board of Ed. It's not even half-way there. And I've said to the Board of Ed, "If you give me something that's half-way there, I'd take it, because this financial – I have refinanced my home, my husband has taken out pension loans to finance our kid's education. We're not doing this because we want to, it's because we have to. So, I told the whole Special Ed committee, "you give me something half-way decent, I will take it." And I don't see anything. It's a disgrace. They don't even get the whole picture. At our school D75 #3, they don't even believe in ABA. They have a few ABA classes, but they don't believe in it. You can tell by how they speak. You can tell by how they present it. You can tell that they don't have the ratio to do what they say they do. If they don't believe in it, then they're not implementing it. And that's the bottom line. So this is bad.

S: Long-term, what do you want to see for your daughter?

D: My daughter? I want to see her continue with the education that she's getting today, without me paying for it. And I want to see her be able to function as her own individual. I'm going to continue to do whatever I have to do. I think medication is important for an autistic child at some point. My daughter is on a med for anxiety. I had that scrip in my bag for half a year before I gave it to her. I gave it to her at 7-years-old, and that was the first time she ever slept through the night. It's not a big difference – but I can function better, and hopefully my child can function better. And she herself has taught me so much. This kid is brilliant. She's smart. She can tell you when everybody's birthday is. She can tell you what day of the week something is. Right now her class is learning all the different state flags. I don't even know that. They have a Spanish teacher now in the classroom. She's telling me Spanish. Just beautiful things that I never thought she'd be able to do. I'm just so thankful. Socially, she's not great socially, but all the kids in her class love her, and they all come to her birthday parties. And she likes one or two in particular.

But social was never a big thing with me. I felt that if they didn't have the language or a way to communicate, the hell with the social. I remember at Early Intervention, they were "social, social, social." Forget social at two and three years old. They can't function. They can't brush their teeth; they can't brush their hair; they can't put on a sweater; they can't say "hello;" – you're going to worry about social? So, I did everything myself.

S: I've appreciated being able to speak with you.

D: I hope I've been helpful. When I saw your email, I thought "this lady has to talk with me." Because it makes me angry – I know parents just accept the programs because they have no choice. And I have very big family support. Listen, I borrowed money from my in-laws, I borrowed money from my parents. I knew I had that support. Everybody does everything for my daughter. And my own sisters who are teachers got trained in ABA to help me. I have wonderful family support, and I know everybody doesn't have that. And it breaks my heart when somebody just accepts a program . . . because that's all that was offered. When the kid is diagnosed you're in shock. On a personal note, I think only within the last year – I didn't even realize I was in depression because I was still functioning. . . . I had to run a staff. I still have 12 people working with her. At a time, there was a staff of 18 working with her. Just coordinating that was like a little business.

S: Tell me about your staff of 12.

D: Well, I have two different paras for the school. The reason why I did that is I was afraid if one was sick, the other could go. . . . I have my lead teacher. I have speech and OT. I have four different ABA instructors that come to my home; I have a [undecipherable] type person who's trained in ABA also; and then I have the school staff – the teacher, the director, and an assistant in the classroom.

S: That's amazing support.

D: Now my daughter is taking piano lessons. My son and my daughter are both taking lessons. They're on like their 4th lesson and they seem to like it. I didn't know how she would do. But she seems to do alright. . . . They say studies prove that with typical children as well as disabled that, children who play piano or other musical instruments show better reading and mathematical skills. So I'm excited about that. . . . We're just really busy. And I have a husband that is just -- he doesn't want to die and say, "I didn't do something." So we apple pick, we go on vacation, we feed the animals, we go everywhere — which is very good for her. . . .

Follow-up Phone Call with Denise on 11/26/03:

I asked Denise about her statement that the Department of Education pays $60,000 per child for a District 75 placement, while her daughter's program (which the Department of Education doesn't want to fund) costs $30,000. I wanted to understand exactly what the $30,000 covered.

D: The $30,000 includes tuition for her private school, plus pays for a one to one para to be with her at school all day.

S: Is the para trained in ABA?

D: Yes, I pay her $10 per hour and she is ABA trained.

S: How about your home services?

D: The $30,000 covers those too. Anna is getting 10 to 12 hours a week . . . . [explains that these are with ABA therapists and focus on supporting Anna's learning in school].

S: How about services like speech and OT?

D: Yah, she's getting those at school.

S: And are those included in the tuition?

D: No, the Board of Ed does pay for those.

Transcript of Interview with Parent C - "Kathy"

"Gary" – 8-years-old
This interview took place on in Kathy's home in Queens on October 27, 2003. Gary was present, but mostly in his room with an aide. His younger sister, Lauren, was in and out of the room asking for help with her homework. The interruptions noted in the transcript were generally interactions Kathy had with her children.

S: When did you first realize that something was wrong?

K: Well actually I'm like a loon. He was my first born and, being a teacher, I read every other book on child development and child care, and I pretty much had an idea of what milestones he should be meeting at certain stages. By 3-months-old, I said to my husband, "There's something not right here, with this kid."... We would have parties here, we would have the TV on at night, and he would sleep through everything. We would bang things behind his head. We had his hearing tested, because we thought he was hard of hearing. And that came back pretty much within the normal range for 3 months. He wasn't tracking, like kids track. He wouldn't look at us, and he wasn't really smiling. He wasn't very sociable as an infant. All of these things said something to me and I spoke to the pediatrician and I kept asking questions – "Why isn't he meeting the milestones like the books say he should be meeting? [Interruption] Anyway, so by 3-months-old we knew that there was something not quite right. . . . And I asked his doctor about it – his pediatrician who hadn't had or didn't know of autism yet – I mean, she knew about autism but she didn't realize at the time – actually Gary was her first [autistic] patient. And because of Gary she was able to get intervention earlier for some of her other patients. She has always felt sorry about not knowing back then, but I love her anyway. Now, whenever I need something, she goes above and beyond to help us get whatever services we need, because she felt badly about not knowing. At the time there wasn't enough information out there for the pediatricians. But because it [autism] has become so prevalent more pediatricians are becoming aware of what the signs are, even at that early stage.

So at 3-months-old we knew something was not quite right. He didn't crawl until like 9-months-old, and he didn't start walking until 19-months-old. By 14 months we said, "Enough is enough." Things just didn't gel. We had him evaluated and, sure enough, that's when we discovered – at that time they still wouldn't tell us that it was autism.

S: How did you get the evaluation?

K: I called up the Board of Ed and they recommended certain places to go to. So we had them come to the home because he was so young. And they evaluated him in the house. They realized that, yes, he does need intervention. So at 14-months-old he started Early Intervention. He was getting OT, PT, speech, and a special ed teacher.

S: And did he receive a diagnosis at that time?

K: No. They still would not tell us that it was autism. And we were still given the idea that there was a possibility that he'd just catch up. We had no clue. He wasn't even talking, he wasn't pointing, and they still wouldn't tell us. I kept reading more and more to find out what was going on with this kid and I couldn't get any answers. At that time I still wasn't even sure. It wasn't until he was about 2-years-old when he started doing the stereotypical behaviors with the head banging and all this other stuff, that we realized that, you know, it started to come together – that it was autism. He still didn't have language, and even then wasn't pointing.

S: Tell me about the services he got at that time.

K: Initially we were getting services three days a week. But now [when we saw these new behaviors], we got really concerned. And, he went to school for half a day and for part of the day he would get home services. This was still Early Intervention.

S: Did you have a case manager working with you?

K: Forget about it. We rarely if ever saw them. I mean, we didn't know. By the time he was 3 he was getting ready for preschool and we were getting very, very concerned. So we joined this organization called NYFAC, New York Families with Autistic Children, where we went to classes to learn more about autism and to find out about schools.

S: Did Early Intervention do anything at all to help you find preschools?

K: No, we had to do the research on our own. We wound up putting him in a school called SE Preschool #3, and we left him there for a year.

S: Was that a private preschool?

K: It was sort of like a private – the city paid for it. But, after a year, and we knew that he was autistic, we weren't happy. They weren't doing the right program. The social worker there was always in disagreement with us. We wanted a very structured ABA program.

S: How did it come about that the city was paying for Gary's school?

K: Because he was already part of Early Intervention. We had the whole meeting with the committee [she clarified, CPSE].

S: What was your memory of that?

K: It's a vague memory. All I know is that the services that we wanted were – at that time because they didn't have preschools that were available and appropriate for special needs children . . . Anyway, so preschool services: Okay, we asked for SE Preschool #3, the school backed us up on it and we wound up getting it.

S: Did you receive any other services in addition to this?

K: No, just the school day at SE Preschool #3. After a year at that school we weren't happy. We didn't like what we saw there for him. At NYFAC we found through being with other parents a better school – a very structured school in the city called SE Preschool #4.

S: Is that an ABA school?

K: Yes, it's a very strict ABA school. And, they got him pretty much on task.

S: How did that transition work with the school district?

K: I went to the committee [CPSE], and I petitioned the committee that I wasn't happy with the school he had been at. And I said I wanted him in a better school.

S: And, in your first attempted they accepted that?

K: Yes, because we went in with a big packet of evaluations and things like that that we did privately as well. We were also upset with the fact that the school board's evaluations of him, in my opinion — well that's another story. I'll tell you when we get to the kindergarten level what happened with the Board of Ed. That's when we had to start fighting. But, pretty much Early Intervention and preschool, we got what we wanted. They weren't going to argue with us.

S: The second preschool, the ABA one – that worked for him?

K: Right. That worked well for him. We wanted him to stay there, but they didn't have room for him. At that point, since he was turning 5 the Board of Ed wasn't willing to pay for it. Especially since they had Special Ed schools for autism. We had to go out and prove to the Board of Ed that the schools they had weren't good enough first.

S: Okay, so he's about to turn 5.

K: Right. That's where the fun began. Early Intervention was a snap.

S: And preschool –

K: Preschool was not a problem. [Interruption] Turning 5 was the hard time.

S: Can you walk me through what happened at that time.

K: Well I brought him to the district office to have the evaluation. And, the first thing I told them was that he was autistic. And I asked them, "do you have a closet?" You know, because they were going to test him in the kindergarten classroom – too much stimulation. "Do you have a closet where you can sit with him, and do you have the appropriate tests that can tell you how autistic he is?" And they said, "No. We only have the routine test for IQ." And I said, "Well you're not going to get an accurate diagnosis of him then, because you're not set up for it." And she admitted to me, "Well we're not set up for it." I said, "Fine." I took notes during this whole process. So I said, "I guess then I'll have to go privately to get him tested and evaluated and you'll have to pay for it." End of story.

So we went privately. We went to Mt. Sinai – they were doing a research project, a Prozac study. So I volunteered Gary for a Prozac study so I could get him evaluated free without having to solicit the Board of Ed. I figured, at this point I'm willing to try anything anyway to see if this will help his autism. It turned out it didn't help his autism anyway, but we got the evaluation – everything, including an EEG, the whole nine yards. So we knew he didn't have any brain tumors or whatever else. Because, there was a kid in his class at SE Preschool #3 who had a seizure while he was in class. It turned out his autism was caused by a brain tumor that caused the seizure. And he wound up dying. He expired in hospital because he never came out of the seizure. So I was very scared when I heard that, and I had the whole nine yards done to Gary. [Interruption]

Anyway, to make a long story short, I had the evaluation, and he was definitely autistic. And they told me what level. He was all up and down in every department. Some things he was high, some things he was low, some things he was a basket case. So I brought the evaluation back to the Board of Ed, and I threw it down on the table at the committee meeting and I said, "Based on this, I want what I want." [Interruption] . . . I went with my husband and one of my husband's friends who happens to be a social worker for the Board of Ed. So he was our advocate. So we went in and they said, "Okay, fine. We know he's autistic and now you need to go out and find a school for him." And they recommended some schools for us, and we went out and investigated some locations. We went to several different schools and I didn't like what I saw.

S: And what was it that you didn't like?

K: They were either too noisy – Gary needs a lot of structure, and if it's too noisy he flips out. If it's too busy he flips out. The school like D75 #5 – forget about it – it was a loony bin. They had kids there ranging in age from 5 (and he would have been a 5-year-old) all the way up to 21. And I didn't think that was appropriate for all of them to be in the same building together. So I said, "No." And they said, "Well it's the best one." I said, "Apparently not for my son." And we went to some private facilities as well. We went to NPS #2. We really liked it. But, number one, they didn't have room for him. And, they said that even wait-listed, the possibility of the Board of Ed paying for it would be – we'd have to *really* fight.

The wind up is that we did find a public school that we liked. And that's where he has been attending now. It's an 811 school. And they happen to have three SI III classes – a low functioning, mid-range, and high functioning group. You walk in there and – I'm not sure if you're familiar with 811 schools.

S: No, tell me about them.

K: The 811 schools are strictly special ed, and the kids run the gamut. . . So it's a very quiet, very sedate, very structured.

S: Is this part of District 75?

K: Yes, it is. It's definitely part of District 75. [Interruption] . . .

So he started out at 5-years-old in this school. He has been there since.

S: How did you find out about this school?

K: Again, going back to NYFAC, it was recommended as a school I should check out. NYFAC recommended it. And his initial teacher there, Sara, happened to have herself a child who was autistic. So she was very familiar with autism, and this teacher was phenomenal. She was no-nonsense, very structured. She knew exactly what to do with the kids, because she had been through it, plus she had taken all the classes. So she had those kids structured. Whenever she was absent, you knew she was absent because we would always get these reports about Gary being obnoxious in class. But the minute she walked in the door, she had those kids in their desks. She had the whole day structured with them. She got Gary talking.

S: How much talking was he doing before?

K: He was doing some talking, but now she had him talking about what he wanted, like, "I want this. I want that" – that was from Sara. She also had him starting to recognize pictures and words, and understanding language and the things around him. She was the one who really jump-started him in this way.

S: An important person.

K: A very important person.

S: Did she use ABA?

K: Yes. She had the day structured – like in the morning, they did one-on-one, and Gary was still getting his speech and physical therapy and occupational therapy.

S: At the school?

K: At the school. He was getting all of this at the school and everything was ABA pushed. The SI III ABA is all ABA. The kids knew exactly the routine. Every morning they knew to take their attendance, they knew to put their things away. She had that class running like clockwork. They had them walking in straight lines. They knew when it was time to go to the bathroom. . . . She had them in check.

S: How many kids were in the class?

K: There were six children, one teacher, a para, and an aide. Because it was a language-based class they also had a speech teacher in the room. So there were 4 adults with 6 little boys. I said, "Forget it. This is perfect. You can't ask for anything more." It was very intense. She really had that classroom running. The para and aide were also trained in ABA – so much so that all of them were able to work with each child. So you had these 4 adults each working one-on-one with a child. The other two kids knew what they had to do in their little cubicle, and they would wait for their turn. The adults would all move to the different children, and it became like a routine.

S: Were you able to observe Gary's class?

K: Yes! It was fascinating to see how she had that class running. And then after lunch they did their social stuff. That's when the cluster teachers would come in and give the teacher a break, and they would do music and gym. Or the library teacher would come in with books and read stories to them. But the aide and the para would sit there and make sure the children were listening and attending and following the directions. So she [Sara] jump-started Gary for two years, kindergarten and first grade.

Second grade he had a new teacher. . . . She was also very good, but not as good as the first one. But she was still very caring. She always kept in touch and let us know what was going on. But by second grade Gary had a problem. I think it was the year we had 9/11. A month after that, Gary was hospitalized. He got very sick and threw up, and decided in his little autistic head that if you take in food you're going to get sick. So he stopped eating for a week. I thought he was eating at school, and they thought he was eating at home. He dehydrated himself and dropped weight and wound up becoming hospitalized for three weeks. And they couldn't figure out anything wrong with him. It turned out to be all behavioral.

So, for the next year and a half he was eating exclusively through an NG tube. In fact we just put the machine away not too long ago. He was eating exclusively through an NG tube. So that was like a year of hell for us. He was going to school with an NG tube up his nose. That's how we got the aide to help us. . . . We wound up getting a one-on-

one health para with him through the day so he wouldn't pull out the tube. And then he would go to the nursing station in the middle of the day where they could feed him. And then at night he would be hooked up to a machine so we could feed him at night through the machine. So it was a mess, and that was like a year-and-a-half of that. He didn't thrive at all. We were looking into other facilities for him, more restrictive environments, where we could get him to start eating again. They called in an ABA specialist to try to get him to eat. They couldn't get him to eat either. They were saying, "We can't keep doing this. He isn't thriving academically." So all of second grade, no matter how hard this teacher tried to work with him, he was totally non-compliant. His school tried everything – calling in behaviorists and specialists. That's why I love this school, because they really made an extra effort to try to help him. But it wasn't working.

So finally, what had happened was that after a year-and-a-half of this, we went to a psychiatrist who put him on some crazy kind of medication, this was last March, to try to get him to eat. It worked for about a month and he was actually doing well in school again. But then he had a breakdown and started becoming violent. He threw a teacher on the floor and he was biting people. He just went completely off the wall -- to the point that we had to admit him to Elmhurst Psychiatric Hospital for about a week to get him off the medication the psychiatrist had put him on.

S: Did they think the medication had triggered this?

K: Yes. And they wound up putting him on a new medication. He has now been taking Risperidal, and he's been taking low dosages of it ever since. Since he has been on the Risperidal, since May, he started eating again. So he hasn't been on the NG tube since this last May. . . . Now he eats on his own but he has to be assisted because we still have to monitor his calorie intake.

S: Is the health para still with him at school?

K: Yes, because they still monitor his eating at school to make sure that he eats.

While all of this was going on we were looking into other schools for him. And the Board of Ed agreed that, because of the NG tube, he needed another facility. They were recommending out-of-state facilities. They sent us to a place in Wisconsin. . . . We went there for a preliminary and we were sort of hemming and hawing with the idea of leaving him there, but we decided to check it out. So the beginning of this summer, I flew out with Gary . . . because I teach and I have off the summer. I was going to stay with him for a week out there in Wisconsin to see if this was an appropriate setting for him.

S: And the Board of Ed would fund this?

K: Right – They paid for our airfare; they paid for everything for us to go out there. So we flew out to Wisconsin to see if he would be able to stay there. After two days of being there I called up the Board of Ed in tears, and Hannah – who was the caseworker for us with the Board of Ed – I begged her to please get us tickets right away and fly us both home. "I cannot have him here. This place is a hell hole." They had children in five classrooms with only two Special Ed teachers. They had children with high school diplomas teaching my son's class because they felt that my son was not educable. They told me this, "He's not educable." They had children with high school diplomas giving out medication to children. At one point one of the RA's, who also just had a high school diploma, showed me the books on the QT. . . . Kids were being given wrong medications and no one was being held accountable for this. At one point my son, who was supposed to be getting a one-on-one was sitting at the table. I went to get a cup of coffee. The physical therapist was there, the RA was there, and the other children were sitting at the table. I come back and my son is covered in bananas. No one stopped anybody. Okay? And that was the point that I knew he wasn't going to get supervision there at all. I said, "This is crazy." [Interruption] . . . I said, "This is crazy. This is not for him." I flew him back immediately because I said, "I don't know what Wisconsin allows, but I know this is not New York state standards. And I called up the Board of Ed and I complained. And I said to them, "I don't know why you're sending our kids there." I saw RA's baiting children so the kid would have a tantrum, so that the psychiatrist would up the medication to make them more sedate. On the weekends, they would spend the whole weekend except for breakfast, lunch and dinner watching TV. They did *nothing* with these kids except let them sit in the TV room. And when the kids tried to do anything else, they got angry at them. That's disgusting.

S: What was the Board of Ed's reaction?

K: They were appalled. They had no idea that was going on. They don't go out and visit these facilities. But you live and learn, and I'm glad I went out there. We also saw another facility out in Pennsylvania .... [describes a well-run institution which they liked very much, but which had a long waiting list and no eating specialist.] So that fell through for us. We were having no luck finding a more restrictive environment.

S: What was your interaction with the Board of Ed during all of this?

K: I spoke with the caseworker with the CSE – this was in the city [Manhattan]. Because now his case was over with the state. Because now, they were trying to move him out of state. This is a whole different issue. He's no longer part of New York City Board of Ed. He's part of the state. And that's where his case is now. He's still staying with the state. He's still allowed to go to school through the Board of Ed in New York because by law he is allowed an education, regardless, until they find a better placement.

So, what his school did this year for him, even though as you can see he is really up and down . . . . as I said, they had three different classes. In the lowest functioning class the kids are totally out of the main loop. Those are the kids that sit there and rock all day or lie on the floor. They're really out of the loop. The middle range group, where Gary was initially, they don't have language. They use pecks.

S: Pecks are?

K: Cards. They move the cards around to show you what they need. Like if they have to go to the bathroom, they take the card for bathroom.

When he wants to talk, Gary does have some language. Like if he wants something, he'll tell you, usually. . . . . They felt that the middle range class was too boring and routine for him, and he imitates a lot of behavior. So they tried him this year in the higher functioning class. He's the lowest functioning in the group. The kids there are very, very verbal, and most of them are reading on level. It's just that they're basket cases socially. . . . .

S: And is this a 6 to 1 to 1 kind of class?

K: Yes. Yes, he has a very good teacher, who calls me up and we talk. It's all still ABA, but they're a little more social and more language-based. There are no pecks in this room, and I never use pecks with Gary anyway because I believe that Gary has the capacity to talk if he chooses to. These other children just don't have language at all and they rely only on their pecks. I wanted Gary to use his words because the real world is not him with this piece of paper, "This is what I want." And Gary can talk if he chooses to.

And so they put him in that class which is only language-based. And they do more academics in that room. Gary is doing this . . . reading program because he has an incredible memory, and instead of learning phonics, he memorizes the words. When he sees the words again, he'll remember them – like sight words, only he remembers more than just sight words. And so that's how he is learning to read.

S: Is he continuing to get other services at the school?

K: He still gets speech. He gets speech five days a week. He gets physical therapy twice a week, and he gets occupational therapy three times a week. [Interruption]

S: School-wise what do you see happening for Gary in the next couple of years?

K: Well now we're at the point where I spoke to my husband. I said to him, "You know what. Let's leave him at this school for now." He's thriving. He's doing well academically. He has a male teacher this year instead of a female, and it's all little boys that are bigger than him. He's the youngest one in the class. So, he's less likely to start issues in that class. He's not going to get violent with them because this guy is tougher. He's very structured also. And the kids are, as I said, bigger than Gary is, so he's not going to try to bully anybody. Although, Gary is a perfectionist. They laugh at him at school because everything in his environment has to be perfect. He knows their routines already and if a kid purposefully forgets to put his homework book in his book bag because he doesn't want to do the homework, Gary will grab the book out of the desk and throw the book in the book bag. I mean these kids are high functioning enough to know enough to conveniently forget their homework. But Gary doesn't let them much to their – and they can't do anything about it [laughs] because Gary is like waving the homework book behind him.

S: He sounds very alert and aware.

K: Aware - yes. Nothing can get past Gary. He checks to make sure everybody has their homework book, and it cracks the teachers up. The teachers are aware of what the kids are doing. In a way they discourage it but they encourage it because it shows some normalcy that those kids are conveniently forgetting their notebooks. But it makes them laugh to see Gary saying, "No you don't."

S: What's Gary's reaction to going to school?

K: It's a routine to him. It's just part of his accepted routine. He knows to get on the bus, he knows to get off the bus. It's a part of his day, what he is supposed to do.

S: So at this point, your feeling is "lets stay here for now."

K: Right – especially now since he's starting to eat more. He eats the same foods every day. He won't eat the school lunch. That school lunch, forget about it. So every day, I'll pack his lunch and he'll eat the same things. . . . I'm just grateful he's eating something. . . .

S: Overall as you think about all you've been through in this schooling process, is there anything that you would change if you could?

K: I think – there were other things that I didn't mention. For example, there were two other schools we looked at – one in Iowa and the "K Institute." Supposedly they have this wonderful program for children with eating issues. And we looked into both of these programs, and they came highly recommended from the behaviorist at from NPS #2 who was trying to help Gary. [Interruption] But the problem with that was that they wasn't part of the New York State Board of Ed -- on their list of possibilities. And these were the best institutions for him at the time because of his eating disorder. We tried to convince the Board of Ed to allow us to go to these places and they wouldn't pay for it. They said that because they weren't schools but more like hospital facilities, and because there weren't schools in the facilities, that it wasn't the Board of Ed's responsibility. They said we'd have to go through our health care. Well our health care. . . . would not pay for it. And Medicaid (because he also has a Medicaid waiver) wouldn't pay for them because they were out of New York state. K Institute, we were all set to go. One week before we were ready to go for an intake they sent us a letter saying, "Don't bother to come because nobody is going to pay for this and you can't afford over $100,000." And the Iowa Institute sent us a similar letter, "Don't bother to come because nobody's willing to pay $30,000." So, we were heartbroken. This was the height of when John was having the eating issue. The Board of Ed wouldn't pay for it; our health insurance wouldn't pay for it. If we were to pay for it, we would be paying for it forever. It would come out of our pockets and we would be poor. I would have to take a second job, my husband would have to take a second job, and we still wouldn't be able to afford it. So we were really heartbroken. We kept wishing that this were Canada and that we would have national healthcare where it wouldn't matter what your income was, what racial community you came from, that everybody regardless was entitled to health care and what they needed. So that was heartbreaking. . . .

But in the meantime, his school is going to work with us. We're very fortunate in that, and that's why I keep him at this school. His principal, his assistant principal, his teachers – like I've known of special ed schools and people who've worked in special ed, that feel that some children aren't educable. And they'll just sit there while the kids are in their wheelchairs and watch them like babysitters. But in this school, I can go there anytime during the day and they'll have these kids actively engaged. . . .

S: Potentially, how long could Gary stay at this school?

K: Potentially – I've seen kids there who have fur under their noses. Even though it's supposed to be an elementary school, I think they go by cognition. They do have a middle school but that's in a different school, and they do have a high school and that's also at a different site. But I've seen kids that are 13 or 14-years-old and are there because they're in a wheelchair and cognitively they're like 5 or 6 months old. . . .

S: It sounds like you've found a school that's a good fit for Gary.

K: Yah, we were lucky. We were very lucky. I was stunned because the Board of Ed doesn't usually have [interruption while Kathy responds to her daughter. The tape ends on that side]

S: What advice would you give to a parent who was just starting out in this whole process?

K: The first thing people want to know is, "Where do I go to get my kid evaluated." I usually say, get a parenting magazine or one of the parenting newspapers. Look through the newspapers and find a place that's close to you. Look through the numbers they have there and call up and make an appointment, and get your kid evaluated. If you're not satisfied with the results, find another place. You're entitled to as many evaluations as you want until you get what you think is necessary. If you're still not satisfied, tell the Board of Ed, you're going privately and that they need to pay for it. But the first thing you need to do is find a place and have your child evaluated. It's your right. They cannot question you. Once you put in the papers they have 30 days, and you need to know that.

S: And do they give you a list of places where you can go to get evaluated?

K: Well, they do, but if you're not sure or if you think your child is having an issue. . . . You call up the facility and make an appointment to have your child evaluated, that's what I would tell them. Sit down, listen to what they have to say, and talk to them about what you have to say. If you're not in agreement with them, go somewhere else. Keep getting answers and don't give up. You are your child's best advocate. Keep lots of records – names of people you spoke to – and keep files on everything. Accumulate those files so you can use them.

S: For instance, how would you use them?

K: When you go for your evaluations you have all these different conflicting views, and you could show that something is not right. "This person is saying this, but you're saying this, and then that person's saying that. I'm not getting my answers. I want answers, and if you're not giving me answers because three different people who are sponsored by the Board of Ed are saying three different things to me – it's time I need to go someplace else. And it's up to you to pay for it because nobody can agree what's going on with my kid. It's my right to know." The documentation gives you the power to say that. The more documents you have, the more power you have because it shows that you've tried.

And one of the things I always tell people too, when you go in for your meetings, take a picture of your kid with you.

S: And why is that?

K: Because it gives a face to the person you're talking about. I don't like taking Gary physically with me because I feel that he disrupts the meeting. But if I have his picture sitting there, they'll see that the person we're speaking about is not a piece of paper. He's a living human being. This is the person we're talking about. This is my son. This is who he is. And I keep the picture next to me, so that they have an idea that they're talking about a human being.

Also, parents should bring an advocate with them – someone who has been through the system. I know that when you go there you're entitled to have a parent, but this is a parent that they assign. So they're all familiar with each other. Bring someone else with you.

S: How do you pick someone to go with you?

K: Find someone who has already been through the system. Go through support groups to find someone. Some of my parents of the children that I teach, I tell them (even though as a teacher in theory I'm supposed to be on the side of the Board of Ed), I tell them if they need me I am there for them. And I will come with them to look at facilities for their children and help them place their children in an appropriate facility. I've been through the system. I know it stinks. I will sit there at the meetings and I will help them fight for their kids. . . . Never compromise. Go in with an agenda of what you want. [Interruption]

K: I know that having a support group is very important. It helped to be able to talk about feelings and stuff, and to be able to get ideas and bounce ideas off of people.

S: What could the people in the Board of Ed do that would help all this work better for families?

K: Listen to the parents, because they know their child better than anybody else. With me, I think they listened, but they didn't want to hear. Everything is budgets and money. They're going to try to put a child in the least restrictive environment – well you know what I'm talking about – the least expensive. We're talking dollars and cents. So they're going to try to do what they can do because they're told to, because of money. And you've got to be firm and stick to your guns and know what's best for your kid. You are the only advocate for your child. . . .You do what you think is best for your child. You go in with an agenda. You go in knowing what you want, and you demand it. Don't ask for it. You demand it. And if your needs aren't met, then you sit there and you will not let that meeting end until you get what you want. Keep arguing with them and arguing with them until finally you break them. Don't let them break you. Okay. Because they'll try to break you in those meetings. I wanted 5 days a week speech and I got it, for 30 minutes. I tried to get home intervention but unfortunately the Board of Ed stopped doing home intervention as well. So I have to go through Medicaid now – were trying to get res-hab for him. We got physical therapy, we got the occupational therapy. You've got to fight for what you want and never give up. It takes a lot of strength and a lot of patience. . . . You need to be consistent and follow-through and keep documents. Very important – follow a paper trail. Write dates and times of every phone call, the name of every person you speak to, and keep it on file. Keep careful records of everything. I have like [with her hands indicates a large stack] from like the beginning to the end in order of everything. Keep all the IEP's, everything.

In regard to family, we used to go to a support group, but not anymore because I don't have the time. [Interruption]

S: Anything else that you'd like to say about all of this?

K: Boy I wish I could turn back time. I wish I could turn back the hands of time to when he was like three months old. I mean I tell my husband, "you can't go back in time. You can only go forward and do what you can do." But knowing back when he was 3-months-old what I know now, and the fact that we weren't sure but we were sure something was not right. I wish I could have been more convincing. I've become more assertive-aggressive because of the whole experience. Now I fight more for him and his needs, but, what if? What if we had started when he was 3-months-old, and had not waited until he was 14-months-old? Would it have made a difference in his life? What if we didn't put him in the SE Preschool #3 – which was a horrible school? Would it have made a difference if he started ABA when he was much younger? Would it have made a difference?

I remember when he was 3-years-old I got so angry at him one day because I was told that he could talk if he wanted to talk. He just needed to learn, "give me." We used to have a gate by the kitchen . . . I was in the kitchen and he wanted something. At the time, I did know what he wanted, but I wouldn't give him what he wanted until he did this [shows the ASL sign for "give me"]. He threw himself on the floor and tantrummed, and went ballistic. I took his hand and I kept saying "give me," [indicating the ASL sign], "give me, all you have to do is say give me and I will give it to you." And even his sister who was only a year old, toddled up to him and took his hand and went like this [ASL sign] too. . . . Finally he just got up and went like this [shows the ASL "give me" sign]. I was like stunned. I was in shock. He did do the sign for "give me," and I gave him what he wanted. I said, "Good Gary, 'give me,' now it's yours. And that's when we finally broke the ice with ABA. And that's when we finally got him to start talking because after that, everything was "give me" [again shows the ASL sign], which was powerful. So we taught him that in order for him to get something he has to show us and tell us. We went from "give me," and eventually he would take our hand and lead us and show us with his hand. So, now he knew that he wasn't going to be a passive person in the world, that he had to communicate. [Daughter returns with another homework question. I turn off recorder and we conclude the interview.]

On December 10, 2003 Kathy and I spoke on the phone and I asked her to clarify which services Gary was receiving at age 2. She said that he attended a half-day therapeutic nursery school and then had OT, PT, speech and special ed at home. She said the occupational therapist was ABA-trained and began implementing some ABA strategies with Gary. This worked well and convinced Kathy that ABA would be good for him. She said however that EI wasn't supporting ABA at that time.

Transcript of interview with Parent D - "Carolyn"

Carter -- 5-1/2 years-old

This interview took place in Carolyn's office in Manhattan on November 3, 2003.

S: Tell me about your son.

C: I have a son. He's going to be 6 in December, and he has been diagnosed with autism – first PDD and then autism, at the M Center. . . .

S: How old was he when you first suspected something was wrong?

C: He's my first child, and so I think that delayed my suspecting. He was about 2, and he started going into his own world. It was pretty terrifying. Because he had been very related. Now when I look back after knowing more and reading more and hearing more, I can see that there were signs of things, where he didn't answer us. But, there was a lot of relatedness. It was really when his brother was born that he really declined. You couldn't get him to look at you, he was in his own world, he was gone.

S: Was he saying any words at this point?

C: Yes, lots of words, once. You know, beautiful pronunciation – like "elephant" – clear as a bell, one time. So we know his hearing is okay. Yah, I made a list. There were a couple of hundred words that he said, and little sentences and things. But he doesn't use them, and we may have heard them once.

S: Once you suspected a problem, how did you get into the Early Intervention system?

C: I think I was so panicked. I called around to see where we should go for an evaluation. I heard about the M Center most often, so I went there for an evaluation.

S: Had your pediatrician given you any information?

C: We went one time and talked about having our son evaluated. But my husband and I talked ourselves out of it somehow. Then the next time we saw the pediatrician a few months later, my son was staring out the window, and the pediatrician looked at me with tears in his eyes and said, "Get him evaluated." You know, I guess I just thought he was a character. I didn't know and still don't know developmental stages. It's hard to keep up with what's appropriate that he's doing. So we went to the M Center and had him evaluated there. It was – my husband is not very stable, and I actually haven't seen him for 3 years now. . . . I think he couldn't handle the information. So I've been alone with it.

But what we did at first, Dr. M diagnosed Carter and advised us to get ABA therapy. We started getting it from the M Center which was very expensive and not covered by insurance, and we just really couldn't afford it. So we were looking for other options.

S: At this point were you having any contact with Early Intervention people?

C: My son was just turning 3. So, when we found out what the diagnosis was and started finding out stuff, he was – by the time we would be able to get into the programs – he would have aged out. Because there was a waiting list. So it was *very* frustrating. A terrifying hurry up and wait thing.

S: So you couldn't have gotten services anyway because of the waiting list?

C: Yah – just like this woman at YAI., "Judy," has been enormously helpful. But to get an evaluation, to get more evaluations – yah, it's months. You get on a waiting list, or your appointment is months later. And so you have this panicked feeling of "hurry up because it's about early intervention," but I don't know what to do and we can't get help because nobody has time. It's pretty terrifying. . . . I just remember I needed to get evaluations in order for the Board of Ed to pay for what he needed. And so the way it happened for me was that Judy pretty much explained what steps I had to take, because I was so freaked out. My husband had freaked out, and all of a sudden I'm alone and I'm trying to figure this out. And, here at work, they're not real tolerant for problems that people may have. . . .

S: Can you tell me more about how you got connected with YAI?

C: I think it was from calling around, and Judy was the most patient, and explained things and was very understanding about the position of the parent, which I think a lot of places are not. They're sort of like "deal with it!" And you're like, "I want to deal with it but I don't know how to deal with it." So anyway, she was really great and so we went there for the remaining evaluations that we needed to do. And through the therapist that we had coming to our house once a day for an hour, she told us about SE Preschool #1. So it was a lot of word-of-mouth things. My son went to SE Preschool #1 for two years, and the Board of Ed payed for it.

S: Can you tell me about how that came about.

C: I went to a committee meeting where we had to talk about the evaluations and the recommendations that they thought Carter needed.

S: What were the evaluations saying?

C: I can't even really remember. It was just that he needed OT. He needed speech. He needed ABA. He needed a lot of directing.

S: So the Board of Ed was willing then to pay for SE Preschool #1. Did you have any difficulties getting that?

C: No I didn't. When I went to that meeting, I was really prepared. I was terrified because of hearing other parents' experiences. So, I was really prepared, and I think that there may have been some sympathy for my situation – that I was a single parent and also had a younger child. They understood that it was an overwhelming situation, and so I think they were more helpful -- fortunately. . . .

S: You said that you really prepared yourself. Can you tell me a little more about that.

C: The thing is that so much has happened since then. And it's funny because my younger son, I started to worry about his speech. He's very related, no other things but the speech, because of his environment of having an older brother that doesn't speak. So we had him evaluated, and the M Center thought that he needed speech. Then I started calling around to people – like the woman that's in charge of District 3 . . . who has also been really great. I called her about my second son and she said, "you remember what happened?" And I said, "you know, I knew you were going to say that. But I really don't remember." It's a lot. It's like you're so in the here-and-now about all this stuff that you have to do, to figure out.

So I guess you talk to the Board of Ed. You need to send a letter requesting evaluations, so then they pay for the evaluations at the YAI. And then with those evaluations you go back to the Board and something is recommended for your child.

But you really need to know what the options are before you go, and what your child needs before you go. They don't start offering you stuff that your kid needs. You've got to know. And that's scary.

S: Yah. Especially when it's your first time.

C: Uh huh. Yah.

S: So were you thinking of the SE Preschool #1 before you went to the committee meeting?

C: Yes, and I knew that there was a place. I had found out about it from the therapist we had coming every day. Her friend was the head teacher. So, it was really who you know, and people knowing that there was a spot. I was so really, so overwhelmed that it was even hard for me to just do the research about the different schools. I needed people to just say, "go there," people that I could trust with that information. So I was really lucky with that.

S: Tell me about that school experience for him. How was that?

C: Great, really great. I don't know what I would have done. He was in a couple of different classes but then he stayed with one teacher for about a year and a half. He got pendency. Because he has a late birthday, I kept him there for an extra year. I just felt he needed consistency, and it was really helpful. He was there 9 until 2, every day. It's ABA-based but they're not fanatical ABA. They really work with what works for your child, which is really important I think. Because every child is so different.

S: Was Carter getting occupational therapy and all those things during his school day?

C: Yes, and then after school he had through Thera-Care, he had 15 hours a week of ABA and 2 hours a week of OT, and 3 hours a week of speech, for a total of 20 hours a week.

S: And was the Board of Ed paying for that?

C: Yah – and then that's the next hard thing. Nobody wants to take the Board of Ed because they don't pay fast enough. So then you can't find therapists because they don't take Board of Ed because the Board of Ed is so slow at paying.

S: So you find your own therapists, but they have to be willing to take Board of Ed reimbursement, and you found people that didn't want to?

C: Yah. Yah. Like right now, one of the therapists, the speech therapist that Carter goes to, doesn't take Board of Ed, but I'm trying to get my insurance company to pay for her. I think that should work – so we'll see – it hasn't so far. So that's a whole thing too. They give you a list of people that are Board of Ed. The first OT that we had was absolutely a nut. And then we had a speech person that came to our house and she – their list, I think it's more people that are really not the creme-de-la creme. Because, there was this other woman that we had for speech. She'd come to the house and, one time she brought her daughter and then she said she was going to leave for awhile. It basically turned out that my babysitter was babysitting her daughter. And then something happened and I got mad at her and she started crying and she was telling me about how hard things are for her, and I was just like, "Okay." So we got another one. . . . .

We were very fortunate, the OT that we had did take Board of Ed. She's now the head of the M Center OT and really capable. So now I have Carter going to see her once a week after school, which is not covered by the Board of Ed, but she's amazing and very effective. You just come to realize that you just have to beg, borrow and steal to be able to — She was the first therapist to come in because she was the first person I found with availability. It was also through SE Preschool #1, the head teacher, she knew of this person – it was people knowing people. She brought Carter to the park when he couldn't stand being at the playground. He had to get out of there. The kids' voices, everything, he'd just take your hand and pull you out. And he wasn't always like that – it started around when he was two when he started really closing down. Anyway, she made him do stuff and now he is just absolutely amazing. He's so agile, all over the place, trying things, really amazing. She made him do stuff and he'd resist, and she'd so it with him – go down the slide and go through the tunnel. She was like unbelievable.

S: That's wonderful.

C: Yah. We were so fortunate with her. She really helped wake him up. And the ABA really helped wake him up too. I think he has outgrown ABA therapy, but it really brought him back.

S: So he was at SE Preschool #1 for a couple of years, and then what happened?

C: Then it was all kind of nutty. I had already looked for another school for him because he was aging out. It was like, can I get pendency, or, maybe I can't so I have to find out what the schools are. I had to get a lawyer to help me with the pendency thing, but just in case I needed to research all the schools to see where he might fit. Because a lot of people told me that the Board of Ed doesn't do pendency – "It doesn't happen," "You won't get it," – parents kept telling me that. So we were pretty lucky that we did get it.

So I had already done some research for schools and this year there were some new schools to look at, and some schools that had been new had some more history and were more organized. Because, there were some that I didn't think were organized enough the first year. I had a really bad experience with where we did decide to end up going. . . .

I have a whole file of who I sent all of Carter's reports to. You have to get updated reports from teachers and therapists, and there's a constant thing of updating the reports. The schools will only accept reports that are only this old or whatever – and so you have to keep renewing things. I probably sent out packets on Carter – like he was running for office – to 20 different schools. . . . [She showed me a large spread sheet that listed the schools and the dates when she sent them various reports and evaluations] This is how I kept track of where I sent what when. This is just the most recent one.

S: That's amazing. What a good idea.

C: I felt so crazy. I didn't know who I had sent what to – I have journals on each school, with phone calls and whatever. You can't remember who you said what to – so I have all this journal stuff because I was so overwhelmed and was forgetful. I just recorded everything, which was great because I could just go back to where I left off. If somebody called me, I'd just remind myself of where we left off and then I could -- you know -- so it was a lot of organizing. Which is very maddening too because you'd rather be spending the time with your child. It's such a Catch-22. . . . . Sometimes I didn't like the reports that people wrote. Sometimes they'll write reports that are more severe, that make the situation seem more severe. And they warn you, you're going to be upset when you read this – it's going to be painful to read, but it needs to say this so that he gets the help that he needs. So, it's hard.

The school that we decided to go to this year – I was so excited because Carter's brother could go, because they had some kids that were more typically developing. They had some kids coming in with speech issues and so it was perfect. Will needed some help with speech because of his environment – I felt. (I didn't really think it was something that was going to be a problem, and I still don't really know because he's just 3-1/2.).

The NPS #3 is where we were going to go. And it was $31,500 a year for each child. They were going to give me a discount for Will – I can't remember what that was. You know, it was like a huge, scary – oh well we'll deal with this year and maybe the Board of Ed will pay for part of it. They don't pay for all of it – that's what I was hearing. And so, I was just going to try to figure how I could do this. I found a way to make the deposit in the beginning. Before the first day, the teachers came to our house, which was really great, and met the kids. So the kids had a familiar face when they went there. It was really very well done. And then the first day of school was just for a couple of hours – we just went for a visit and saw the class and saw the teachers there. It was all really nicely done the way they made it so easy for the transition for the kids. . . .

Meanwhile, just before that [the beginning of school], I had visited the NPS #4, which is connected to SE Preschool #1 in that it is under the AHRC organization. I had seen that school and really liked it a lot, but then NPS #3 just seemed like – it was not so far away, they both could go there – I was so excited about that.

So, first day of school, we were just there [at NPS #3] for a couple of hours and I realized . . . . [talks about what happened and how she realized that the school was not appropriate for either of her sons, and decided not to go back].

So I called NPS #4 where I had gone and thought would be good for Carter. And I had just told them that Carter wouldn't be going there. . . They still had Carter's place. And then I called the preschool that I wanted Will to go to and they still had a place there. So, in the same day everyone was somewhere else. It was insane. It was just unbelievable.

S: And this just happened?

C: Yah. It was September 8th.

S: How are both doing?

C: They're doing unbelievable. I'm so glad. . . . But now the thing for Carter is that his commute is an hour-and-a-half to Brooklyn. So he's on the bus twice a day. Three hours a day he's on the bus staring out the window. I'm like – oh man. But the school is great. His teacher is great. She is so energetic. He likes going. The principal has been really great. I've had issues with the bus driver. But that's a whole ridiculous thing. You can't imagine. This bus driver – coincidentally we had this bus driver this last year for a small amount of time. I don't know why it switched, but for some reason this woman – well I caught her sleeping in the bus a couple of times . . . and so I think she hates my guts, and she is like giving me a hard time again. It's just like the chances of having the same bus driver - it's unbelievable. And it's this woman. She's like -- last week two mornings she left without Carter. We were there and she says we weren't there. I don't know what she's doing or where she is, but we were there. When that happens, I don't get to work until afternoon. . . . . So the principal at the school has been helpful because I've been explaining to him, "Look, you know, this sounds crazy, but I really think this bus driver has a personal problem with me." . . . So this person that's the bus driver can – everything is so precarious because, "Is she going to be here?" We come down early – we're there at 7:15 . . . .

He gets home between 3:30 and 4:00. And then he goes and he has OT on Mondays, and speech on Tuesdays and Thursdays with his brother, which is really great because this person who has been with him for more than a year, teaches Carter and his brother how to play games together.

S: And you said they "go," so this doesn't happen at home?

C: Right, right. These are out. So the babysitter is bringing them around town.

S: Leading up to this school year I imagine you met with the CSE – in May or whenever.

C: Yah, I think it was in May.

S: Can you describe what you remember about that.

C: One thing that was really great is that the teacher from Carter's school [SE Preschool #1] is very articulate, and is really helpful for me – I mean she's on the phone during the meeting, but she is really helpful in getting them to understand what it is that Carter needs. . . So I was at the meeting. They write the IEP there and think about the goals that need to be written on the IEP.

S: Are they paying for —

C: Yes NPS #4 is paid for by the Board of Ed.

S: Entirely?

C: Yah. Except now I just found out that my lawyer, she went to a hearing and got payment for the NPS #3 because I hadn't told her we weren't going there. I had gotten a hearing cancellation in the mail, and I needed to call her about "what is this about," and hadn't. Then I found out that she went to a hearing and got payment for NPS #3, and then at that hearing found out that we weren't there, but at NPS #4 instead. I was like, "Oh man, why didn't you guys tell me you were going to a hearing." So, they're a little miffed at me about that. So right now I hope there's not going to be a problem about payment – that's where I'm going. Oh man, I hope we don't find out all of a sudden that Carter can't – Because when we first got to SE Preschool #1, the first day of school, we went there and Carter was there for the day. I went and picked him up at the end of the school day, and the principal said, "You know what. You can't bring him back until next week because we don't have the right paper work." I was like "Ohh." And that day I broke my foot – carrying Carter. Carter wanted me to carry him. So I carried him and we were on Broadway and 66th and I twisted my foot in a pothole and broke my foot. And Will wasn't even walking yet, he was 7 months old. . . . It was just so – you fall apart. You just do. You fall apart. You're exhausted. You have babies – both guys are up all night. You have to come to work. You know, I work all day and they count on me to be here, and they're mad if I'm not here. So, there's no tolerance anywhere for anything. Ah man. It makes me so mad. I thought about writing Hillary Clinton or someone. It's like, "hello." . . . You know, my family, total denial. Out of sight, out of mind, can't deal with it.

S: Your family?

C: My personal family. My mother and my father are totally in denial. So it's really like you don't – like if an individual doesn't have unspoken support –

S: Where do you find your support?

C: I have a babysitter who has been so great, that I depend on a lot. It's an amazing situation. She's from the Philippines, and she has her family in the Philippines – her daughter and son and her husband. Which I don't know how she does it. She's here to make their lives better. So for me, she's basically on call for me. I can call her up and say, "Can you stay overnight because I have a business dinner tonight." I am really lucky. She comes on Saturdays. She is really so amazing. It's very expensive though, and everything goes to this time in our lives – to therapies and – there's another therapy that Carter is doing right now. It's an auditory listening therapy at the Spectrum Center. It has been really effective with him, just amazing.

S: And what do you see happening with it?

C: It's a combination of the listening therapy and OT. And he is so much more present since he started doing that and word searching, and much more related. His receptive language is incredible. It's quite effective. So, he's doing that again right now. He has tomorrow and the next day for this one loop they call it when they go for a week and a half.

S: So at this point, hopefully the Department of Ed is paying for his school during the day. And then the extra therapies afterwards?

C: I don't think they will. I'm going to see if I can get Will's paid – he's going to have some evaluations. I'm going to see if there's some coverage there. I'm trying to get insurance – because I've heard other parents have gotten – but then that's another thing, fighting with the insurance company – you can't believe. Things bounce back to you and it's just phone calls and letters and unbelievable. So I've never had any of the M Center stuff paid for, just because I haven't had the time to fight. I'm starting to more now. But, a year and a half ago, no way. Now that Will is in school and that's going well, things are starting to flow. Carter is getting very responsive and Will is developing, and he's getting protective of Carter. Will is more like the older brother – you know, things are getting much calmer. In the last 6 months or so, like during the summer, we'd go out into the city — the 3 of us. Before I was terrified to go outside with them because one would go that way and one would go that way, and I'd be like – But now, they'll stay with me. Carter will still float away. He's so quiet you have to kind of like remind him that he has to stay with us. But Will will – it's amazing to have a child that follows you around. It's amazing. It's absolutely amazing. . .

S: So to make sure I understand. At this point then, the Department of Ed has said that they will pay for a non-public school for Carter. The payment hasn't necessarily come through yet –

C: Yah. I'm kind of sitting quiet right now, because I'm afraid that — Oh you know what happened during the summer. This is what happened. We were half-way through summer school because Carter is on a 12-month thing. We were half way through summer school and the principal at SE Preschool #1 said to me that -- technically the school year is from summer school until the end of spring. . . . So Carter is half-way through summer school and they say to me he's actually not eligible for being in school right now. And the way I found out about this was because of a problem with the bus company. What was it? Carter, because of his age, he couldn't ride the bus with pre-school kids. He had to ride the bus with school-age kids. So he had his own bus every day. They called it the yellow limousine at school. Because they'd pick up Carter – the driver and the matron – and they'd drive him to school. And then they'd pick him up after school.

S: Oh – that must have cost so much.

C: I know. It's so insane. It's just absolutely insane. So everyday all last year, Carter had his own driver.

S: All year?

C: All year. But then in the summer there was a glitch with the school bus. I can't remember what it was, but I was calling the bus company to find out about the bus. Somehow through that I found out that there was a problem with whether or not Carter was eligible for summer. Because technically the year ended in the spring. So he wasn't really supposed to be there. I was like . . . it was all of a sudden the rug pulled out from under you when you think things are going along. So the thing was, it turned out to be really kind of great. The principal said if I bring him to school every day and we don't press the thing about the bus, that she'd just look the other way and he could continue through the summer. So I brought him to school every day and the babysitter picked him up every day. We just didn't do the bus. But it was great because he was right across the park. It was wonderful to take the subway with Carter every morning. It was great to have to do that. . . . .

S: It sounds like you've met some pivotal people along the way who have been helpful.

C: Yes. I don't know how people can do it without that.

S: I have a couple of more global questions. One is, if you were talking with a parent who is just now getting their child evaluated -- at the very beginning -- what advice would you give them?

C: A neighbor of mine just told me about a friend of hers who is pretty certain that there's something developmentally wrong with her child. I haven't met this person, but I told my neighbor to tell her to just go get the evaluations – if there is any wondering at all. Just get the evaluations. Just know that you're going to hear some really tough things and you're going to wonder, "Are they true? Are they not true? Are they more severe so that he gets what he needs?" And it's terrifying, but just do it. Because the earlier, the better. I regret not knowing earlier. Now, with my second son developing more typically, what a blessing to be able to experience that. I mean in a way I think that Carter is divine. He is in his own world; he's a happy guy. I hear lots of stories in parent groups about other kids that are tough and bite and are angry. He's a sweet guy, so I'm very lucky for that. I mean, he makes me see the world different. You just see things so differently. I feel wiser for having Carter. But, then the beauty of how things click with a typical child, it's just amazing. So, I'm lucky for both.

S: And it sounds like they're lucky for each other.

C: Oh – they're so great, the two of them together. They wrestle and play. I mean, Will really did – Carter was not responding to anybody and Will was not having it. He was a little guy and he wanted his big brother's attention, and he got it. He would like be in his face and sit on him, and make it so Carter absolutely had to pay attention to him. . . .

S: So you advice to parents: It sounds like # 1 is, if you have any questions, get an evaluation.

C: Yah. Just go see what people have to say. That's the hardest part I think. It's very hard to get the information that your child – you know. I just thought Carter was a character and fabulous, and I was mad if I heard that somebody thought that he was slow. I heard that my ex-husband's family were having discussions about the fact that Carter was slow. I was like, "What!" I was so mad. I think probably people are afraid to say anything because that reaction is kind of normal. But you've got to set it aside.

S: Do you think you'd be more likely to say something to another family member if you observed that they had a child that didn't seem to be –

C: Well I'd figure out how to say it. Maybe you can't just come out and say it. But I think if somebody had said to me – if the pediatrician or if somebody – I think our pediatrician isn't very knowledgeable and that was part of the problem. If he had been more adamant about us doing something earlier, we would have been - because I think he kind of thought maybe something might be going on, but. You know, it's hard. I guess I would just try to figure out a way. I think if someone had said to me, "I have to tell you something and it's really hard information to hear. But you have to just kind of weigh it out because it's critical now." You know, that's the thing. Because it's about earlier. And it's such an epidemic that you start waiting in lines for things. So you're going to lose time anyway. So don't lose time in evaluation.

S: Once parents get the evaluation what else would you suggest?

C: Listen to other parents and their experiences – which can be terrifying. I mean I would go to this parent group and leave more freaked out. It's a parent support group – but not what you'd expect, not like "oh I'm going to go feel better." It's not about you. It's about finding out how to deal with stuff and who to deal with, and exchanging experiences. I think that's really important. That has been really important for me.

And I think also just sort of setting aside – you know, things like the principal at the SE Preschool #1 was very supportive sometimes. She's a tough cookie. And everybody was a little afraid of her. She runs a great place. She's good at what she does, but she's a little bit scary. You just have to set aside – basically, you need to set aside your relationship with people when it involves – it's like being a politician. It really is. It's crazy, but it's like that. You can close the doors. Like with this bus driver. When I talked to the principal about it he said when he called the owner of the company -- who whenever I would call the owner of the company, he would just scream at me on the phone. You're just at these people's mercy. So the principal of the school calls the guy. He called me back after talking to this guy and he goes, "Well he's not the easiest guy in the whole world to talk to. I let him go on for about 3 or 4 minutes about you." And I said to the principal, "I don't know why we're talking about me. It's not about me. Carter needs to get to school. That's what it's about." But, you know, these weird relationships start to happen which hinder things. Carter gets to school late or he doesn't get to school because this woman is mad at me for some reason. So anyway. I think that's a lot too – to set aside – you know you're the advocate. You're the advocate. I guess that's what it comes down to, and it's not about you. I've heard parents say like, "Oh I talked to that person on the phone and they were so rude, I just never called that school back." And it's a great school. There's so much psychology to all of this. That's the thing. So many hard things to do in terms of letting things go that, you know, that are difficult. Man, it's hard. First of all, accepting the fact that your child might be less than perfect, and it's your child. And then your parents are freaked out and in denial. And then I'm mad at them, and then – you know — all this stuff, and then just getting through the system. It's just incredible. You know, I was thinking that 5 years ago I would have never thought I would be able to do what I have done. Really.

S: What has gotten you here?

C: It's just like persevering, I think. And realizing that it is not about me, and it's their [unintelligible word], and I've got to do this. So, anyway, it's just an unbelievably overwhelming thing to go through, and I think that the tolerance – especially in a city like New York. I was talking to my mom yesterday about how there was somebody trying to get around us. And everybody is just impatient about our pace. And I'm like, "Too bad, we're doing great. You're just going to have to get over it." Like one time Carter and I were going up the subway stairs on the way to his school and this woman behind us says, "Oh the whole world has to wait for you two." You know, you get stuff like this all this time. You're trying to show Carter how to put the pass in the bus thing. It's important, all these little things – give him some empowerment. So he's putting the pass in and the bus driver says, "If you guys want to play, go to the park." It's like all the time you get these things. The intolerance you have to live with too is just -- you're bombarded. . . . .

S: In terms of negotiating with the CPSE and the CSE –

C: The preschool system I think is much easier than the school-age.

S: How do you see that?

C: Well I think the people are nicer. I think that the population they're working with are little kids, that they don't have a lot of problems with them or whatever. But I think the school-age, they're tougher. The stories I've heard — people think everything is all set and just fine, and then [an administrator] will walk in the room and say, "Oh no, that's not the way it is. Your child is not going to this school," whatever. And in a moment everything – you know, the power that they have is scary. And with the amount of cases they're dealing with, they can't give the attention. But actually there was a parent -- what was she? The parent something of District 3 called me the other day to let me know that she was the new parent representative or something. And then by the end of the phone call she had helped me out with some of the bus issues. She said, "you know what you can do. You can get a note from your pediatrician that his bus route needs to be shortened. Because he's the first and the last to be picked up, maybe he can have his own bus again this year, and it will be a shorter bus trip." Which would be more important than last year for him to not have such a long commute. So she was pretty great.

S: And she was a parent?

C: I wrote it down [checks on her computer]. Lets see. "Teacher assigned for Carter's review team." So she's not a parent, she's the teacher assigned for his review team. And she's with District 3. . . . She was really nice. I was amazed. Somebody was calling me to tell me that if they could help me I should call them. And so I called her again when there was a thing with the bus again, and she was going to do some research for me.

S: That's nice to hear.

C: Yah. That was pretty cool. You know there's people.

S: If you were in the position of advising the Department of Ed, what could they do to help this process work better?

C: I don't really know. I think like to have this person that you feel a connection with, that you feel you can get real advice from. You know, she's a person who *can* tell you what you could ask for. Where for the most part with the board, you're pretty sure they're withholding information because they can't pay for everybody's everything. Which is horrible.

I think that one thing too that amazes me. Actually the board had recommended a school . . . [near where we live]. And I thought, "Oh wouldn't it be great if that was a great school. Then Carter would just go down West End to school." And I went to the school, and it was just a . . . . holding tank for mentally retarded children. I asked about parent groups or if I could talk to other parents whose kids were at the school, and the woman got tears in her eyes and said, "Parents are really not involved. A lot of these kids get bussed in from the Bronx and from Queens." So how ridiculous is that? Carter is getting bussed out to Brooklyn. These kids are getting bussed into our neighborhood, and the school is just absolutely awful.

So I think the board needs people to help them — you know, between Carter getting bussed by himself all year so unnecessarily last year – you know, it's like they have to have their rules, but, come on! They have all these fiscal problems and just in terms of bussing that I know about myself, from my experience – the expense of bringing kids in and Carter out, and Carter by himself and all that – could be classes, could be learning.

So I guess to have more neighborhood people that are focused, maybe parent groups in neighborhoods that have more of a focus and attachment.

S: Anything else that you'd like to say?

C: I feel like we've covered a lot of the frustrations and the overwhelmed -- so many things to figure out, and that it's the luck of the draw if you can connect with someone who can help walk you through a stage. It would be nice if there was some kind of guidance. Because everybody inventing the wheel is exhausting everybody.

On December 4, 2003, Carolyn responded to my email question about what if any therapy Carter had before he turned 3. She responded:

Before Carter was 3, I paid out-of-pocket for 1 hour a day of ABA therapy with a very good M Center therapist. Carter needed much more ....urgently!

It was a terrifying time, because I was understanding how much Carter was digressing while finding out that there was such a huge demand for help for many children and not enough helpers, and then also how out of reach the expense of the critical therapy was.

Transcript of Interview with Parent E - "Barbara"

Jeremy - 5-years-old
This interview took place at a Manhattan diner and while walking to pick Jeremy up from OT, on November 3, 2003.

S: When did you first realize something was wrong?

B: Basically what happened to us was, I had a 4-year-old, my daughter Emma. So I had the experience of having a very typical child. Also, in my family my sister-in-law has a severe – at one time they thought he was autistic . . . It turns out he's not autistic, but he's mentally retarded. He's not toileted, he doesn't talk. He is a life-long care case. So I was kind of familiar in a way with having a special needs child in my family. But, it always comes as a shock.

At 2-years-old, Jeremy said like two words. I kept thinking, "this is not right. This is not right." But even at 18 months, he had a DPT shot to which he got a severe allergic reaction. He had serum sickness. So basically after he had this shot, the DPT, he kind of went into this mode where he wouldn't look at you, he was lethargic.

S: And before that he had been --

B: I felt like he was. If you spoke to my husband, I think it may be different than if you speak to me. But I think a mother's relationship with a child, whether they have a disability or not, is different. Jeremy always looked at me, he always answered to my voice. But there were clear signs like, he didn't point. . . He never would grasp. He didn't have a pincer grasp. But we thought, "Oh he's a boy, whatever, fine motor." But at 18 months when he got this shot, and it sent us into the hospital, and we were really scared, my husband and I. . . . . It was Thursday. My babysitter called me because I worked part-time. She said like, "I'm changing him and he has these hives." I was like, "Alright, give him some Benedryl. I'll be home at 6 o'clock." I came home and as the night progressed it got worse. And then Friday it just got worse. And by Saturday morning, I just looked at my husband. I was like, "We've got to take him to the hospital or the doctor or whatever," which we did. His hands and feet blew up and he had hives all over. A very bad case of hives. He wasn't eating – you know, it was very scary. Once we figured out what it was – which it took us 3 days to do that, because it's hard to get in to see a specialist when you don't have a pediatric dermatologist. . . . So in a matter of three days, I saw three different specialists. And the one that I really wanted to see, which I had to see on Tuesday when the swelling was going down already, said, "If you had been here yesterday, I would have taken a picture of this for my text book. This is serum sickness. This is an extreme reaction to something that you put in the child's body. Now think." I said, "Well is it food? Could it be raspberries?" "No. Something you put in the child's body. Now think." I opened up my calendar – "I was at the doctor two weeks ago. We had a full set of DPT, Hepatitis..." "There you go, that's it."

S: Interesting. Wow.

B: Interesting. When I thought about that shot, when I looked back in my records. Now of course, it's a second child, working parent, you know, babysitter, whatever. At nine months he had hives as well, and we remember taking him back to the doctor. But, you know what, that was an allergic reaction as well. That's what we figured out. And so basically the idea is that the more you expose the child --

S: The more serious the reaction.

B: Right, exactly – to whatever it is. So, for example, he can never have a DPT shot again. I don't vaccinate him anymore and I'm very anti-vaccination since that time. I don't vaccinate my daughter either. So basically, if he had to have a DPT – like my doctor asked, what would I do if it was a smallpox thing – I'd leave the country. Because something terrible could happen to him.

When he had that DPT – after the DPT, everything became clear. It was like gee he doesn't, his immune system is so weak and he doesn't really talk and he doesn't have the pincer grasp, and he likes opening and closing the doors of the cabinets. Why is this? . . .

So that happened in March/beginning of April. In April we went to Florida to see my parents and I started making phone calls. Through my sister-in-law I was able to get into Life Start program. Now, how did I even know about Life Start, was through my sister-in-law. My sister-in-law was really, an immediate family member who really, really helped me.

S: Tell me about Life Start.

B: Life Start is one of the agencies that is like one of the Early Intervention agencies.

S: So they do the evaluations?

B: Yes, right. And then they give you the therapists and whatever. And they have coordinators and they have program people, and they have support groups for parents. I had a very good experience with Life Start . . . .

So, he was given a full work-up evaluation. I had a social worker assigned to my case, which is what you get in EI. A very lovely woman, really kind. . . . And I started doing a lot of reading. I quit my job, gave up my job as education director of a non-for-profit arts and technology organization, went very part-time – one day a week – and really devoted myself to "what am I going to do with this kid." I went to Dr. M.. Dr. M. is like this very well-known, expensive developmental pediatrician . . . and she started a school . . . So I went to see Dr. M. Well first we had the evaluations from Life Start. This was the summer of 2000. We had all the evaluations and the social worker came and saw Jeremy and said he's "PDD-like." And I was, "What do you mean? What is that?" And that was intense. At the same time, my husband took a job in Philadelphia because he got caught up in the Internet craze. So he was in Philadelphia, I was home with two kids. I was like lying on the couch. I went to my therapist and went on anti-depressants. Because it was like, "How am I going to function?" I have two kids.

So, then with Life Start – I had like 12 hours. And so I called my sister-in-law and said, "Okay I got 12 hours – 2 hours speech, 2 hours PT – I don't know how I'm going to schedule that." And she kind of laughed and said, "Barbara, you need more hours. You need more hours and you really should see Dr. M, and use my name. . . . You've got to see her, and maybe he needs ABA." She was really like very intense there on the back scene. So we went to Dr. M. Sure enough after the two evaluations that she did – I walked out of there and Dr. M was like, "This is the hardest day of your life. Your child is on the spectrum – it's PDD, absolutely." Jeremy is in the background with his trucks, you know.

S: Did you have to pay for that second evaluation?

B: Yes, I did. That was a private evaluation. And that's the other interesting thing about this whole special needs world. I'm lucky enough where I could quit my job because my husband works for a Fortune 500 company. He has a 5 day-a-week job, we get all our insurance through him. I send my daughter to a great public school but we live in Tribeca. I mean, I'm incredibly lucky. I have all my family around to support me. My mom lives in Florida and they have an apartment in New York. My in-laws live on Long Island and they have an apartment in New York. So, we're a very close knit family. Special needs is really like to me, if you want to see your kid get well, it's an issue of race and class. It really sucks. It really, really sucks. I mean it breaks my heart. But it's like I could afford to pay $2500 for Dr. M's evaluation. . . . My husband is not an investment banker, but we have enough to have priorities in our life. And our priorities in our life are our children and family.

So anyway, we saw Dr. M and she's like, "You need 20 hours of ABA." So she's like, "Here's this phone number -- two phone numbers." So I called this one phone number of a therapist. . . . Now Tribeca is a very small community, so there's only like two preschools. Now already my daughter was attending one preschool and I have a lot of friends who attended it. I remember my girlfriend Alice would constantly say to me, "Oh I see this one little boy has a great therapist," and we would constantly talk about it. I don't know why. So anyway, I knew that this woman Shelly was already working at the neighborhood school. When I called her up – this was the day I got the diagnosis from Dr. M, I literally lifted my head up from the pillow and got on the phone. I was like, "I live downtown. I know you work downtown. We have a friend in common. Will you come see my son? I'll pay you privately until you can get on the case via Life Start. I'll take any hours you can give." And Shelly came on my case — she's the young 28-year-old, very motivating ABA therapist, who really structured the team. She brought with her, by November, another therapist – this other woman named Amy. And between Shelly and Amy, this little boy is like - it's incredible. Neither of them have children. Amy is 45-

years-old, never had children, never will have children. She's so devoted. She went to visit her sick mother in the hospital on Friday and then she's like, "Oh I have to be with Jeremy on Halloween, so I took a car service to come and be with him."

So I'm incredibly lucky because I have been able to hold together five of the nine therapists that I've had for the 3 years. And people think that's kind of unusual, but a lot of people tell me that it's because of the family. Meaning that, I resist and I cry about it and there's constant battles with me at meetings and whatever, but we constantly have open communication. I'm constantly saying stuff like, "Okay I got this catalogue. What toys do you want?" Or, "I read this article. I'm passing it around to everyone." Or, "You went to a conference. Can I have your notes?" It's a lot of open communication. The therapists are like saying, "We want him off the bottle." One day I come home and one of my therapists is like, "We've stolen your bottles. Use cups." Now interestingly enough other friends of mine would have been really insulted to have gotten that. And I was like, "okay." It's funny and I appreciated the sentiment of it. I'm not saying I'm a marshmallow, but I feel like mantra is "Is this going to be good for Jeremy? And if it's going to be good for Jeremy, then I'll adapt and my family will adapt.

S: A few moments ago you used the word "team." Can you tell me more about that?

B: Okay. So the team means OT, PT, speech, and 3 ABA ladies.

S: And this was the team you started out with after –

B: Yes, after my evaluation.

S: Tell me about how the hours went during the week.

B: Okay. So basically, when he was 2-years-old, that's when the program really went into full swing. And it was the summer of him being two years old – he turned 2 at the end of August. Now in Tribeca – it's a very small neighborhood as I said before – a friend of mine signed her daughter (who is my daughter's age) up for this little play group. So when I went to see the playgroup when my daughter was little, I signed Emma up and she called me back and said, "I only take 6 kids Barbara. I can't" – You know people put their name on when they get pregnant. So when I got pregnant with Jeremy, I put his name on. And I called Joan up and I was like, "I had a baby. I want Jeremy to go here" "Fine. You're in. You're the first one on the list Barbara." Now here it is cut to the chase two years later. Joan calls me and she says, "Okay I need your deposit." I'm like, "Joan, wait a second. Let me just let you know that we just got a bad diagnosis. This is a little boy with severe developmental delays, etc. Do you still want him?" "Absolutely. Bring him to me. I want him. This is my specialty." I said, "How about he has a shadow there with him?" "Great."

So, that's what I did. At 2-years-old he was in a two-day-a-week playgroup. So he would go to the playgroup with a shadow. So that was like 6 hours a week.

S: Was this someone you hired?

B: No it was all through Life Start. I haven't paid for any therapy in the past 3 years privately.

S: That's remarkable.

B: It is. I haven't paid anything privately – except Dr. M. That's a doctor though, which I got reimbursed for from my insurance – just 50%, but it was 50%. And of course hearing I do separate, and eye doctor – all of that, of course.

S: Okay, so 2 days a week he had the playgroup.

B: He had the playgroup with a shadow – a SEIT from Life Start. So I had 10 hours of SEIT, 20 hours of ABA, and then the other 10 hours was broken into 3 hours of OT, 2 hours of PT and 3 hours of speech. Forty hours. So he has been working 40 hours non-stop since he was 2-years-old. Other kids would go to the park. He would be home, at his table doing matching, doing colors, writing his name.

S: How was that for him?

B: You know what's sad for me is that his childhood was like usurped. What's great is that there are certain people that tell me – and I knew Dr. M said to me, "you have until he is about 5-years-old. . .until their personality sets and who they are will set. The brain is elastic. Play with it. See how you can pull it to the way." And you know what? That was my goal for 3 years, from 2 until 5 – it's really 2 to 6 now because he's having therapy a whole extra year – my goal was to see how much we could change the brain. Without Prozac, without medication, with eyeglasses, with some homeopathic vitamin B therapy, with intense therapists. When a therapist would call me up in the morning to cancel, I'd immediately get on the phone with all the other therapists. "Can you come today? Do you want a make-up session? Great. . ." I was like a maniac. Not only did I make myself a maniac, but my 3-day-a-week babysitter, I made her a maniac too. So much that actually, you know when she started with me she was in fashion design, and now she's going back to school to get a PT degree. She realizes this is where she wants to be.

S: Wonderful. Okay so you got EI --

B: Okay, so I had EI services for that year, 2 to 3. I went into a support group. I tried to drag Laura along. Laura couldn't do the support group. She's kind of closed – I'm more emotive. She's like, "this is my lot in life." I'm like, "I'm going to change it." or "I'm going to do it differently." She's different. She couldn't go to the therapy group because a lot of times a bunch of mothers would just sit there and cry. You know, and she couldn't do it. She's like, "This is a waste of my time. I can't do it. I need to be home with the kids." So we started our own support group, Laura and I. I met Laura through the small special needs world. And I was like, "Look we really need another place to talk." Gradually over the year, she just took over the group. She organizes it. I go, like five times a year - it's once a month. But I was really going to this other support group that I just stopped going to.

So Jeremy had therapy 2 to 3 [years old], you know communication notebook, good days, bad days, wasn't really talking, was racing around this woman's loft looking at the white reflection of the wall. We did all sorts of things. We bought him a weighted vest. We bought him a weighted blanket. We bought him weighted T-shirts. He wore hand weights. I put him on the wheat-free, gluten-free, casein-free diet. Just recently this summer, I've let him go off. He discovered bagels with my husband – two Jewish boys – and he can't help it. . . I'm a total believer in that diet . . . The other thing I did for him is that at two years old, my speech therapist looked down his throat and said, "He's got really big tonsils." So I went to see a guy and they took his tonsils out. He had "kissing tonsils."

So it was a combination of thinking about looking at the medical things we can do – like lets get rid of his kissing tonsils, lets get rid of his adenoids – maybe he has sleep apnea and he's not getting a full night sleep and he needs to be rested. Lets go to the eye doctor – he has a double A stigmatism like my husband, so he started wearing glasses at 2-years-old. So I started doing all of those little – you know, take him to the neurologist, take him to the eye doctor, pediatrician, whatever.

S: What happened at the end of Early Intervention?

B: At the end of Early Intervention, everyone was very nervous about going to the next level of CPSE. It was like, "Oh, will you get your hours?" whatever. It was funny because we got all prepped to do it. Laura prepped me. She was like, "Okay, bring a notebook. Make sure you have everything – like the IEP in your notebook, and all the phone numbers of the therapists, and a picture of the kid, and everything." She's like, "It's going to be very, very business-like, so try to make it humane. Show them you're prepared – have a notebook, take notes – show you're really on top of it." But everything she said was right. And I went in there –

S: Did you go alone?

B: Oh no. I went with my husband, and one of the therapists came, and then they give you a liaison at Life Start. And so we went in there, and I remember I met my husband at Starbucks in the morning because I dropped the kids off at school. He walked down the street and he was wearing this beautiful white shirt and a tie, and he's a very casual dresser. And I'm like, "Woah." And he's like, "Look Barbara, appearances mean something to some people." And he walked into the meeting and he really charmed the pants off of the District 2 person who was like a troll. But in the end, it was like my husband and the troll. It was like black jack. They were bargaining. My husband was like, "Well, ABA runs in 2 hour sessions and we really need another 2 hours." Because, you know, we had rehearsed what we absolutely wanted bottom line. And so he was doing the negotiating. It was like, "We really want to the 2 hours." "Okay, but then I can't really give you the 4 hours of OT, so how about if I take away an hour of OT?" And my husband was like, "Okay, signed, sealed and delivered if I can sign it right now. I'm ready to sign it right now if I get that. 20 hours of ABA. Fine, I'll take that 3 hours of OT." Because in the back of my mind I knew that if I really needed more OT, I could go to my insurance company. I knew that from other friends – from speaking to parents – that speech and OT are reimbursable, but ABA is not. So we did like rehearsal things of all of that beforehand.

So I went to CPSE and it was really no problem for me. And then it became – my story became so famous at Life Start that they asked me to speak to the transitioning parents from EI to CPSE. I spoke to them twice. And I put this talk together. It was called, "Ten things to Do at Your CPSE Meeting." It was like, "Prepare a notebook. Take an advocate with you." This kind of thing. So a lot of parents called me after that – because I gave out my email and phone number. People would be really nervous that they wouldn't get the amount of hours that they wanted. But, just one of my hours was dumped down.

So then I was in CPSE for 2 years.

S: And during that two years?

B: During that two years, for the first year – the first year was 9/11. Jeremy was set to go to the little preschool right here called Preschool #1, and it was the second day of school. He was going to go with his shadow and everything. He had been there for camp over the summer so he was very used to it. And then he also would go to therapy all – until like 6:30 or 7:00 p.m. every day – so that's how I would fit it in.

S: And did he do the therapy at your house?

B: Yah. My house became and is his therapy center. People come into my house and they're like, "Oh you really like toys and games." I'm like, "They're all therapeutic. They all have something to do with getting him to do something. So

S: Second day of school

B: Second day of school, okay, so we flee and we relocate up to my mother-in-law's apartment on the Upper East Side.. And I'm freaking out. Now am I freaking out because — okay, I got my daughter resettled, my husband resettled, everyone. And I'm thinking, "You know I don't want my son to suffer because of 9/11, and he still needs his therapists." So the therapists redid their schedules to come uptown. A lot of them are only downtown therapists, so that was a hassle. We'd have to shave off a half hour here, 15 minutes here, because they were traveling all over. There were families here living in Chelsea, there were families living in West Village, everywhere. Then the hard part was finding a school. To try to get into school on the Upper East Side or West Side, as you know, after school has already started, is a nightmare. Basically, I called my friends at Life Start. They gave me a bunch of numbers, all these temples. I called all the temples, one after another. No one would do anything. Finally, I called – you know who has been incredibly supportive of me, is the Early Childhood Direction Center . . . And this is a resource in New York City that people don't really know about. [Describes how something helped her get a spot for her son in a program at the 92nd Street Y] . . . not in the nursery school, but in the little program that they do. I mean when people heard that, they could not believe it. Free. I didn't have to pay anything.

S: Who paid for that?

B: It was part of 92nd Street Y's "give back to families downtown." So we did that. We signed him up for Friday classes. And then I did a couple of tours and I heard about this other great place that I often refer people to. There's this woman named Robin and she runs a very small preschool on the Upper West Side . . . And I called her up and told her my situation, and she was very cautious. She said, "It's in the middle of the school year Barbara." Because by the time I got my act together it was the end of September, early October. I was like, "Look. I'll take any spot – morning or afternoon. I'll take one day, I'll take two days – whatever." And it was this constant thing. And she let him come in for two days. And then eventually . . . she said, "Okay, let him come in for three days." So he was doing three days a week with a SEIT – my SEIT – and then the Friday morning at 92nd Street Y. And I transferred all of my therapy uptown. And we were living in a one-bedroom apartment. And we did that for four months.

S: And how did he do in the school-settings?

B: You know it was just – the whole period was like an adventure. We were living on the Upper East Side, we'd take the bus to the Upper West Side. He loved that. It was just an adventure. He's an adaptable kid. He doesn't tantrum. That's not his thing. Kids are so different. It was kind of like I learned from my therapist that you've just got to take him by the hand and move him around the city. And it worked.

So we stayed there for four months and then my husband and I were like, "Do we sell our apartment or what do we do?" In our heart of hearts we were like, "We love downtown. We live downtown for a reason. We have our friends here, our family, great public schools. We hated living uptown. So we moved back downtown. And so then, everything resumed. Jeremy went to Preschool #1 for the next couple of months, February through June.

Then I started thinking about my next master plan. My next master plan was, "I don't really like Preschool #1." The teachers are — They don't really have an education. You pay $10,000 a year for these private nurseries and you get these teachers who don't have masters in education. You have BA, maybe. What's a BA? Nothing. You don't know how to structure a lesson plan. I walked into the school one day to pick up Jeremy, and I saw on the calendar that they were doing dinosaurs, but they were doing like Jurassic – they were doing time periods of dinosaurs. I looked at the teacher and I was like, "I know Jeremy doesn't understand this, doesn't get this. Do any of the other kids?" She said, "Oh well kind of." But I knew. It was a lesson plan way, way above. There are so many ways to be able to do that. You know my background is, I worked in the Guggenheim Museum in the Education Department for ten years, and I also teach at SVA, so I have life-long learning. My mother is a teacher – I have that in my blood, and I know what is appropriate for a kid at certain ages. I learn all the time and early elementary isn't my specialty at all.

S: But being a parent you get a sense of that.

R: Right, from being a parent. And I knew what Emma was capable of. I just said to my husband, "Are we going to pay $10,000 for another year of this, and just be unhappy and unsatisfied. He was like, "No, what do we do?" I thought: I'm going to put him in pre-k, public school pre-k. I have my babysitter. It's pick-up at 11 o'clock. It's not a problem. So he goes from 8:30 until 11:00. And the whole reason I'm going to do this is because my hope is that I can get him into the inclusion classroom at PS/I.

Now there are two schools right here. PS #1, where my daughter goes, and PS/I. I knew from being in PS #1, that Jeremy wouldn't be able to hack it there. So, in April of that year, when it was registration.

S: So this is April of when he was 3?

B: Yes, April of when he was 3. He was going to turn 4 in August. I called up the principal of PS #1 . . . and I said, ". . . it's Barbara Klein. I have a little boy. You know he has special needs, and I want to put him in the pre-k at PS/I." "Why? Put him in pre-k here. It will be fine." I said, "I want him in pre-k at PS/I because ultimately I want him to be in an inclusion class at PS/I." And she said, "But Barbara, I'll give you a para." And I just said to her, "But then he'll be the only odd little guy with a para versus being in a classroom with a special ed teacher and with 10 other kids with IEP's." She said, "Okay, bring the paper over. I'll sign it." She had to variance me off to PS/I, and she did. So then I got into PS/I.

S: What happened when you went back to the CPSE that year?

B: Oh, I didn't tell them where I was going. You don't have to. You go back just to renew your hours. So they renew the hours. It's like, "Okay, how's he doing? Great. We see justification for all these things." They don't need to know. "Great. Fine. Good."

So here's the thing. When I went to get the variance and I signed him up for PS/I, I didn't tell anyone that I was bringing a SEIT with me. I walked in the first day, with the teacher, and with the principal, and I said, "Oh Jeremy is 4-years-old. He gets CPSE services, and here's his SEIT. So the SEIT is going to be accompanying him in the classroom. Okay?" And the teacher was kind of like, "Another set of hands in this classroom with 18 preschool kids that are going in different directions." So there was a teacher and an assistant with 18 kids and my shadow.

Now the problem with pre-k was that we had a very bad teacher. She could barely manage the class. . . . I went and I spoke to the social worker and I spoke to the principal about it and everyone agreed. There were complaints coming in about her. She wasn't good. I would give her special needs books. It would be like the kind of thing where the kids would come in in the morning, and you'd say to her "My father is going to pick-up today," – she couldn't do two things at once at all.

S: It sounds like being around other children in groups is not distressing for Jeremy.

B: No. He doesn't have behavior problems. He doesn't tantrum. This is what he has: odd behavior -- he flaps his arms. He licks he lips now. Also he jumps, he gets really excited. He doesn't know how to initiate with kids, like "Hi my name is Jeremy. Play with me." That's all learned behavior for him. That was really the beauty of pre-k, was that he got to kind of learn that before he had to start school. So my feeling was that his being in school-type playgroup environments since he was 2-years-old, really contributed to what he is today. He loves kids. . . . For him it's like, he doesn't want to be alone. When Emma is not around it's like, "Where's my sister?" She's the same way. I have a very empathetic daughter. She is like an angel. . . . She helps Jeremy so much. Even walking Jeremy to speech therapy, she says to me today, "Mom, Megan is working on his r's right? But she also really needs to work on his l's, because he says little lulu, he says it wittle wuwu." . . . She's incredible... very aware. She's not aware that he's "autistic," I don't use that word. She's aware that he's special. In fact she was describing to me another friend of hers in her classroom who also has a special needs brother . . . and was saying, "you know, me and Elena are so much alike, because we both have brothers that have disabilities." And that was that. . . . She's kind of magical. And she's like his angel. He is in love with her. She is his perfect model, and she's willing to do it. Since she was 6-years-old it's like, "Who is in Jeremy's room. Can I go in and play with them?" And she was always allowed to go in at the end of the session. The last 15 minutes they can play together, all therapists.

[A break while we walk to Jeremy's OT center. Then we start talking again about Barbara's preparations for CSE]

B: And I sat with some of the Life Start ladies – this is when he was still in pre-k. They said, "What are you going to do next year." I was like, "Oh I don't know. I guess I'll apply to all those schools . . . and then I'll think of inclusion. I'll put him in the inclusion class." And then one of them looked at me and said, "you're not going to go for pendency are you?" And I looked at her and said, "what's that?" And she said, "Oh no, I probably shouldn't tell you." And I said, "Well, the cat is out of the bag. You're going to have to tell me now." And she told me. And she told me basically what pendency is. It's not a law or anything. It's just a state of being where the Board of Ed and the parent disagree so the services continue.

So I called my sister-in-law and I was like, "I need your lawyer." There's like 5 special ed lawyers in the city and they do all the cases, and so I said, "I need your lawyer." And she said, "Okay, here she is." So I met with the lawyer last November, and she said, "I'm so glad you're here early because people usually call me in April. I was like, "No, were going to do this." And she told me the steps and she guided me along the way.

And the steps are basically, you've got to go through with the Board of Ed evaluations, everything. I did all my homework. I mean, they didn't even recommend schools, but I went and looked at the 6 to 1 to 1. I looked at the 12 to 1 to 1 – all in District 2. I felt so prepared that I felt that if they were going to say, "he should be in a 12 to 1 to 1," I'd be like "No way, because you're grouping kindergarteners, 1st and 2nd graders together. I went to see the classroom over there. There's no way I'm going to put my kindergartener with a 2nd grader."

S: So you did all this looking before you ever went to the committee meeting?

B: Yes. You know, I speak to a lot of parents and also my lawyer helped me. And also, I'm probably a little "autistic" myself in that I'm a very visual person. I think of all the steps, I outline them, I have to write them down. I have to be well-prepared. I have a degree in art history, and I always say to people, "That degree probably got me nothing, but I'm a great researcher. I really know how to research." And that's really what I do for Jeremy. I've been able to uncover layers.
[Interruption again as we greet Jeremy]

B: Once you get to CPSE, therapists don't want to work with our kids, because they don't want to work with the Board of Ed. One, they notoriously pay late – versus working with an agency like Life Start, which is like EI, or Stepping Stones or one of those other agencies. So, they notoriously pay late. Also, they don't pay as much.. . . So you either have to be lucky enough to have EI therapists that become so attached to your child that they'll just do it anyway, or you have to find new therapists. A lot of it is, does the therapist want to work with the family? I'm close enough with my therapists where they'll say to me, "I can't stand this family. You cannot believe what they will do." And because you're walking into someone's house – Do you want to walk into a dirty house? Do you want to walk into a disgruntled house? Or, do you want to walk into a house where it's nice, where the parent offers you a peanut butter and jelly sandwich?

The oral part of Barbara's interview ended here. On November 21, 2003, she emailed her response to the question, "How could CPSE and CSE work better? (See below) Prior to that, in response to a question about what advice she would give new parents, she sent list of suggestions she developed for parents she spoke to at Life Start. This is included with her permission, and contains several minor changes in punctuation and spelling.

Barbara:

How could the CPSE and/or CSE systems be improved? Firstly, I feel like a lot of what CPSE and CSE see in the kids they evaluate are MEDICAL conditions. ADHD and Autistic Spectrum Disorder are NEUROLOGICAL conditions and they are not LEARNING disabilities like dyslexia. Having an IEP with a label of speech and language disorder can mean so many things: Is the child processing language? Is there apraxia? Is there an oral-motor condition? I feel that CSE's mandate is to give the least amount of services for a child in that they either want the child classified as a SPECIAL NEEDS CHILD or a mainstream child.

When your child is in between those two, that is where you run into problems. Take the case of Jeremy: He is not a mainstream student. However, putting him in a special needs classroom either 12:1:1 or 6:1:1 would put him with extremely impaired students. I've visited these classrooms and most of the kids are either in foster homes, have had no previous therapies, or are grouped together inappropriately.

My only choice was to put him in an inclusion class where--there are TOO many students -- 23-- even though there are two teachers. In my parent teacher conference this week I told the teachers that to be honest the class is too big for him, lunchtime is overstimulating. The teachers are overworked. They don't really know how to adapt the standard District 2 curriculum which is abstract, at best.

The comparison between what Jeremy is getting in this Board of Ed school and what he could be getting at a Board of Ed-funded PRIVATE school like NPS #5 is huge. I just

went on a tour there and the specialty is language immersion, small class sizes and giving the students the tools they need to perform well academically. Why can't there be more schools like NPS #5? Why can't the Board of Ed realize they can't do everything and perhaps give out some grants to start some NEW SCHOOLS for this in-between population? No one can do everything well. And, I really think that the Board of Ed needs to realize that these in-between kids will be more productive citizens if they get the tools they need at an early age.

So, back to your question about CPSE--which is still very nurturing and you can get a lot of services at age 3 and 4 vs. CSE which is age 5 and up and wants to basically just categorize your child as special ed or not, is a complicated one. For me, CPSE works okay. The problem is

CSE, and putting together schools where children with different learning styles can function would be one of my main suggestions. . . . Also, the people that they have working at CSE to do the psychological testing are the WORST, and private schools won't even take Board of Ed reports!

It would be helpful if the CSE was unconcerned about how many therapy hours they are giving you vs. how they can help your child. I honestly felt that the people at the Board of Ed were trying to NOT give Jeremy what he needed to succeed in the classroom. For example, they didn't even offer him a para when clearly he needed one...and of course, I didn't push this at the meeting because I was prepped by my lawyer not to say anything, just take notes and that any mess up on the Board's part would be advantageous to Jeremy's case, which ultimately it was.

There are kids in Jeremy's class who so clearly need a para, but, probably due to money and lack of knowledge, they don't have one -- money because the Board of Ed doesn't want to spend a lot of money per child, and lack of knowledge by parents about what their options are.

If I could change something about them, what would it be? Dismantle the system....learn from other school systems in California or Chappequa, NY where they are truly trying to give children what they need and deserve. . . .That is what the current administration is trying to do --dismantle the Board of Ed and its bureaucracies. I'm not sure they can though, without starting from scratch. Sadly, more kids on the spectrum are being diagnosed everyday, and sadly, more children will be slipping through the cracks. Ultimately we could end up with a population in society that can't read, can't make change in a store, can't lead even semi-productive lives. There really needs to be a concerted effort about how to educate children with different learning styles. How will this happen? It really is scary. Maybe people like you and I can make a difference through advocacy and information. That is my hope.

TOP TEN THINGS YOU CAN DO AS A PARENT OF A SPECIAL NEEDS CHILD:

1. Attend or start a support group.
2. Keep a notebook of your thoughts, ideas, questions – record everything including behaviors noted, therapists' ideas, books you need to read, phone numbers, schedule changes.
3. Be a researcher. Leave no stone unturned. Books to read (about other families experiences) include: Clara Claiborne Park's The Siege; Beth Kelphart, A Slant of Sun; Valerie Paradiz, Elijah's Cup; Catherine Maurice, Can You Hear My Voice; Karyn Seroussi, Unraveling the Mystery of Autism; Temple Grandin, Donna Williams, Oliver Sacks. Websites include: healingarts.org. Defeat Autism Now or dan.org. Do a google search and type in anything – autism, sensory integration dysfunction, hand flapping – your search will reveal something via the web. . . .
4. Explore vitamins and diet. Websites include: kirkmanlabs.com. Read Lisa Lewis Special Diets for Special Needs Kids. Agree or disagree – decide for yourself if the wheat-free, gluten-free diet, casein-free diet is of interest, doable, etc.
5. Catalogues often have better and more educational toys than the local toy stores. Some catalogues include: southpaw.com, abilitations.com, different roads to learning, nasco.com.
6. Connect with your therapists. Listen to them and their suggestions. Make them feel welcome in your home. Tell them what your kids likes or dislikes. Ask them what they need from you so that they may have a successful session with your kid. Always THANK them. A gift may not hurt.
7. Be organized. I keep an excel schedule printed out on my kitchen counter of every single day, every single therapist that is coming. Keep a communication notebook. Keep ten of them – one to stay at school, one for the home, one for the gym. Write notes to all therapists on the outside of the notebook IN ADVANCE of your vacation days, changes, team meetings, etc. Also keep a copy of all phone numbers of therapists, and their schedules in your daily planner . . .
8. Grieve, mourn, scream, get angry. C.S. Lewis said, "No one ever told me that grief felt so like fear."
9. Be a bit of a medical doctor yourself. Of course, go out there and find the best pediatrician who will listen to you and your ideas and encourage knowledge. But, in the end, you decide whether or not to vaccinate, give antibiotics, etc.
10. You will make new friends who you can't imagine not knowing. You will lose friends who have been friends of yours for years. Tell your current friends how important they are to you. Reach out to them and explain and cry and share. Often my strength comes from my friends – the ones that accept your kid no matter what, want to lend a helping hand, a phone call. And this is from my sister-in-law: no matter how much therapy your kids gets, no matter how much he knows or doesn't know, no matter how much he talks or doesn't talk, he is still your child and you love him for who he is.

Transcript of Interview with Parent F - "Michael"

Emily - 9-years-old
This interview took place at Michael's office in the Bronx on November 4, 2003.

M: We have three children. Our second child, our daughter, is autistic. Right now she is 9. When she was about, just a little under a year, we started seeing that things weren't quite right with her. She wasn't really doing the things that her older brother was doing at that age. He's two years older than her.

S: For example --

M: Well she wasn't really paying attention to what was going on around her. She wasn't responding to her name. She had like these very odd ways of playing with toys. We didn't really think much of it. She didn't really seem interested in classic, standard toys. She only wanted to watch certain TV shows. But the primary thing was that she wasn't really indicating anything to us. If she wanted something, she just cried, and there was no attempt to tell us what the crying was about. What she used to do is she would stand in the kitchen screaming her head off, and we just started opening cabinets and showing her things. And when she saw the thing she wanted, she grabbed it out of our hands and ran out of the room. . . .

At first we thought she was deaf because she wasn't responding to her name. And she was about, I would say, 10 or 11 months at this time. So we brought this up to our pediatrician. Unfortunately the pediatrician's response was, "Don't worry about it. Kids develop at their own speed. Don't compare her to your older child – you'll just go crazy." But somewhere along the line there was just something about Emily that led us to believe it wasn't simply she's developing at her own speed. What we saw was that she was actually losing the skills that she had developed. She had been able to kind of mutter a couple of phrases, and just wasn't muttering them anymore. She wasn't responding to her name, she wasn't responding to things we would say to her. If there was a ball in the middle of the room and you said, "Emily get the ball," it's not even that she would just look at you as if she didn't know what you were saying. She kind of just looked *through* you. So that led us to believe that something was wrong.

We finally pushed the pediatricians, and when she was a little less than 18-months-old, they gave us a referral to go see a developmental pediatrician. We went to see Dr. M. . . . So we went to see her just when Emily was about 20 months. We went to see her, and she put her through a whole battery of tests and asked us a whole series of questions, and we learned that the reason why Emily wasn't responding to us was because she was autistic.

It was around that same time that we were starting to learn about things that autistic children needed. Dr. M told us that the local intelligence was that autistic children respond well to behavioral intervention and to speech intervention and to occupational therapy. We really didn't think Emily had any occupational issues though, because she had pretty good fine motor skills, she had good gross motor skills. We were more concerned with her ability to understand what we were telling her, and her ability to communicate with us.

Dr. M then turned us on to Early Intervention because Emily was under 3-years-old. And then we started that whole thing.

S: And how did you take that step of getting into the Early Intervention system?

M: Well it was interesting because we really didn't know how to navigate this whole thing. We were under the impression that Dr. M was pretty much going to set everything in motion. What Dr. M essentially did was make the referral to Early Intervention. This is kind of where things begin to break down. Again, we're talking seven years ago, and it's like night and day what was going on seven years ago and what's going on now.

Seven years ago Early Intervention was – I mean to say it was worse than disorganized, is to be kind. Dr. M gave us some literature on the Early Intervention process. And what we found is there are certain time constraints and there were certain time frames, and things weren't happening within that time frame. We were fortunate, if you want to call it that, in that a very close friend of ours also had an autistic child who was about two years older than Emily. We actually had made plans to visit this friend because she lived out in Queens at the time.... to ask her about things that were going on with her son. Now her son was older than Emily when he started, so he started with CPSE. The problem that arose there was that she never really went through Early Intervention. But she told us about things that her child was doing and the interventions that were involved. It was kind of the same thing, it's just that a different agency was going to administer them. She also gave us some literature on behavioral intervention and other things, and just literature about autism in general.

So we read we these things, and then the things that our friend gave us led to other things. What we decided to do was essentially go out and find whatever we could about autism and what to do about it. Now again, we're talking about the mid-1990's, when you really didn't have much out there on what was going on in the world of autism. So we spent time at the Fordham University library. We spent time at the New York City Public Library. What we were noticing was that the things we were getting were dated from the 70's and 80's, and there was really nothing quite up to date. Fortunately we were able to read this very good book about some work that was being done at UCLA, and about this family in New York that had gone through what we were going through – they had two autistic children. We decided to model what we wanted after that, because all the things we looked at showed us that the behavioral approach was going to be what Emily needed.

The problem was that Early Intervention didn't agree with that. And that started a whole slew of problems. The most difficult problem in dealing with Early Intervention at that time was the slowness. They assigned a service coordinator to us, but I would venture to say that everything the service knew about autism, we told her. She knew absolutely nothing about autism, knew absolutely nothing about how the process goes, knew absolutely nothing about what the children need, knew nothing about how to get the children where they are. I mean all she was interested in was having us sign all these consent form – which I didn't even know what the hell we were signing after awhile.

Ultimately we had our meeting with Early Intervention and, again, seven years ago behavioral intervention with autistic children was like the Stone Age. It was like you might as well curse God rather than get a developmentally disabled kid behavioral intervention. It just wasn't happening. What we found just through networking or getting a name of someone here or someone there – what we found was that there were about three other families in the New York area going through the exact same thing we were going through with Early Intervention as well. The problem arose in that Early Intervention decided to put up a united front and deny everything we all wanted. What they essentially said was they would give my daughter half days of generalized special ed which we could have in our home. But when I asked, "What are they going to *do* with her?" . . . The answer was, "Whatever she needs." And I said, "Well what do you think she needs?" They said, "Well whatever it is that she needs." You know, that sort of nonsense.

So what happened was we wound up having to go to court over it. We wound up educating our daughter ourselves at a tremendous expense.

S: Hiring your own people to come in?

M: Yes – which there weren't any at the time. We actually had to go to New Jersey to find an organization that was offering their services in New York. So Emily was essentially home-schooled from the time she was the day before her second birthday up to the time she was a little over 3-1/2.

S: Did you receive any reimbursement for –

M: Not while it was going on. My wife and I spent close to $70,000 doing this. And this was $70,000 that we didn't have. You know, we maxed out credit lines, tapped relatives. We're still paying this back and it's seven years later. . . . Ultimately we had to bring an action against Early Intervention where we were able to prevail and they did give us a substantial amount of the money back.

The problem was when you leave Early Intervention and you go to the CPSE, which is the Committee on Preschool Special Education, you have the same problems. And again, now we are talking about six years ago, where we had to fight again for these things as well. And I would say, not to go day by day, in all the time we've been dealing with this we essentially had to bring five actions against either the Board of Ed or Early Intervention, in order to get them to agree to give Emily what she needed.

S: Did this include impartial hearings?

M: We'd have to go to hearings, yes.

S: Did each of these cases involve your needing to hire an attorney?

M: Well, Beth and I are attorneys, so we represented ourselves. We're fortunate in that we had that – well I won't even say luxury, because time spent on that was time away from doing other things which would have helped us earn the money to get Emily what she needed and all. But we were fortunate in that we had access to the statutes, we had access to the case law and things like that. For everyone of us, there's a hundred other families that don't have access to that, plus can't afford legal representation. I mean now-a-days things are a lot better than they were then, but essentially the main problem was not really dealing with Emily. That was the easy part. The problem was fighting the system that was out there which seemed to not want to give her what it was that she needed. I mean we had Board of Ed district reps telling us that they weren't going to discuss particular needs because she might grow out of them. But you don't grow out of autism. It's not like the measles where you get it for 10 days, you get over it and then you go on. You don't grow out of it. One person from Early Intervention told my wife that she hoped she was happy over the fact that she was damaging my daughter because she was refusing to do what Early Intervention suggested. Aside the fact that we're attorneys and all, how do you tell another human being that they're hurting their child because they believe something different than the established norm. And the interesting thing about it is that when we eventually did fight them — and this is Early Intervention – we found out that their "autism expert" had not dealt with an autistic child in 27 years, that their program representative knew nothing about the programs that were out there. And these were the people who were telling us, "this is what your daughter needs." So these are the things we've had to deal with.

S: Wow. So what did you wind up doing for her during those years?

M: Well she was home-schooled like I said for the first year and a half. We ultimately got Early Intervention to pay us back for a substantial portion of that. Then we happened to find a school – it's actually run by the AHRC, but the –

S: Can you tell me what that stands for?

M: Oh the AHRC is the Association for the Health of Retarded Children. What AHRC did was around the mid to late 1990's, they began a behavioral program for autistic children, and they happened to have a program that had opened up nearby. . . . So as Emily was aging out of Early Intervention, we decided to explore.

S: Was this an ABA program?

M: Yes, this is classic ABA. And that was a dirty word seven years ago.

S: So they were coming in the home and she was receiving that at home.

M: At home. We started with 10 hours a week, gradually got it up to 20, and ultimately got it up to 42. Then when she got into this AHRC and Emily fit the criteria, so what happened was, we were able to get her a spot in this particular program. So we were able to minimize what she was getting at home and substitute it with what she was getting at school. But at the time we didn't give home services up. She was at school for her 6-hour school day. Then when she came home, she got some additional therapy at home, which, again, we had to fight the CPSE to give her. Their thing was "ABA is the next best thing to witchcraft. You're getting something at school. Therefore our guidelines are that regular students should be in school 25 hours a week. Disabled students, because they need more, should go to school for 27-1/2 hours a week. She's getting 27-1/2 hours a week. Therefore there's no need for any more." There was no thing like this particular child is 5-years-old and can't speak, understands 2% of what you say to her, if that, on a good day, has no play skills at all and has only very rudimentary social skills. They don't see that. We even had someone say, "Well I don't look at her and see an autistic child. I look at her and see a child who needs special ed." I'm like, "That's the stupidest thing I ever heard of." Their thing was if they just gave her speech therapy, that would solve all her problems. I said, "Look you know you can't give a pair of glasses to a kid whose deaf and say 'Look I've helped the handicapped because I've given them glasses.' That's not what she needs." And that was really the main thing at that time.

S: And this was CPSE?

M: This was CPSE. Ultimately what she got out of CPSE we had to go through the same nonsense with the Board of Ed with CSE. Again, if you mention ABA, they hear Pavlov's dogs – you're training her to be a circus act. You know, they just freak out over it. Ultimately we got them to agree to what Emily needed. But, that was after a lot of kicking and screaming, hearings, having them held in contempt, and things like that.

S: And that was because of your experience as attorneys being able to do that.

M: Partially, yes partially. Like I said, we were fortunate in that we could read the statutes, we had access to the case law. There's a thousand people who don't have access to that. Try to explain what's in this book [holds up law book] to someone who, all they know is that they say "hello" to their kid and their kid doesn't say "hello" back to them. I mean you might as well be trying to teach them Sanskrit. I don't even understand everything that's in there.

But we were able to do it and now we got to the point where Emily is in a full-day program. And, through other sources of services that are available, we are still able to give her a couple of hours of more behavioral training. . . .

The main concern though, beyond everything else, is still getting Emily what it is that she needs. Like we were talking about before, with most people their autistic child is either their only child or their youngest child. Fortunately or unfortunately, depending on how you want to view it, we have three children. We have two boys and a girl. The girl is the middle child. What people don't understand about autism is not necessarily dealing with the autistic child, but it takes so much of your energy it's hard not to forget about the other two – who are no less deserving of your time and effort than the disabled child. We're fortunate in that the boys never really resent Emily because of it, because it's all that they know. But that's one of the most difficult things that people don't understand. Also, the constant parade of people coming through the house is another thing. And the parade of people who think that just because we have disabled child, they have the right to tell us how to raise her and how to live – which annoys me more than anything else.

S: When does that come up?

M: Well that comes up with educators who may or may not know anything about autism, when we have to have her evaluated all the time, dealing with CPSE, Early Intervention. As I told you, people in Early Intervention telling me about autism in 1995 who last dealt with an autistic child in 1967. Their "expert" on ABA did not know anything about ABA. These are the people that feel they have the right to tell me how to raise this child. . . .

Anyway, these are the things in dealing with an autistic child that people don't ordinarily know about. Like I say, dealing with Emily herself, that's the easy part. [Laughs]. I mean, you know, you have to spend a little more time telling her to sit down, come to the table, drink your juice, be quiet, time for bed. It may take a little effort. But, that's the easy part. The most difficult part is dealing with the lack of services that are around, and begging for the scant services that are around.

> [Michael's wife Beth came into the office a few minutes back, and now joins the conversation briefly]

B: And the turn-over. We've had people that we've been able to get trained to deal with her, and because the pay for these people is so incredibly low and most of the people we get are college students who do this until they're going to do something full-time. What happens is you get somebody, you're in a groove, things are going well, and then they leave. Then it's like back to ground zero, start all over again. And there have been big gaps in time where Emily wasn't getting anything after school because the agency we were dealing with (which is a Queens-based agency and is top-notch in terms of their training). The problem is that they are based in Queens and they can't get people who are willing to work in the Bronx to go to Queens for the training – it's a 15-session training. So if you're talking about college students, they're not going to have time to do a 15-session training, or if they do, they want to be trained in the Bronx to work in the Bronx. So we have the problem of trying to recruit people ourselves and trying to get them out to Queens, or QSAC has the problem of trying to recruit people from the Bronx to come and be trained in Queens and then go back to the Bronx. They have a hard time recruiting people to work in this field anyway, but add the geographical situation.

S: So there's no training going on in the Bronx as far as you know?

M: No, not formally. [Beth leaves]. We were fortunate enough in the beginning – since Emily was being home schooled at our own expense. What we were doing was Alpine trained people at our home. Essentially what we did was we went to the psychology department at Fordham University and gave a notice to the chairman that said that if anyone is interested in learning this, contact us. We got a couple of people from there and one person from Lehman College, and one person from the College of New Rochelle. We were fortunate in that there is a professor of behavioral psychology at Fordham who is really into promoting knowledge about ABA. Now he's not a clinician. He's a researcher. So he doesn't really know the hands-on, but we've been fortunate in that he has been very good in getting people interested in being trained and things like that. As Beth was saying, one of the problems now is that the people who do our program at home is an organization called QSAC - Quality Services to the Autism Community. They began offering their services in the Bronx, probably about 2 years ago.

S: And is this a range of services or is it primarily ABA?

M: They offer a whole range of services. We're essentially accessing them for the ABA services. But again, it's hard to get people to do this because it is a very lengthy training period. See, when we had someone running the program privately, that person would train them in our home. After we aged out of Alpine and we actually got somebody to do it. She was able to train them in our home. So instead of one hour a week for 15 weeks, she would do 6 hours on a Saturday. It would be very, very intense. Then she would sit with the person while they worked with Emily for maybe a month. Then what she would do is she would sit in one room and the person would be in the other room with Emily, and if there were any problems she could always ask. Then she would do it by phone, and then she left them alone.

S: At what point did you have her involved?

M: This was after we aged out of Alpine. We aged out of Alpine when Emily became CPSE-eligible. She was actually 3-1/2 at the time. And when she got into the AHRC school, that's when Alpine phased out. But we wanted to keep the after school program going. So one of the people who was working with us in the Alpine program – actually, 4 students stayed, and one of them who had a little bit more experience than the others, would kind of coordinate everybody's activities.

S: Like a team leader?

M: Sure. Sure. What we then did was we actually found a woman who was an ABA coordinator for a school out in Queens. We asked her if she would be interested in supervising our program at home. She agreed and that was fine and she took over. But then at point in time she went back to get her PhD and we lost her. There was about a year when we didn't have anyone supervising the home program. And we were kind of stagnating. What we decided to do was there was one girl who was in the home program from the very beginning, and she had been there for about 3 years. She was pursuing ABA as a career, behavioral interventions as a career. So she had just gotten into graduate school, and we asked her if she would oversee what was going on and she agreed. At some point in time though, graduate school and this became a little too much. So there was about a year when things leveled off. We didn't have anybody who could update Emily's program. So we were kind of stuck on the same things over and over. That was about a year.

Then, just through the internet, Beth was involved with this – it wasn't a chat room – it was called the Me List. It's sort of an email system that went back and forth, an email network on behavioral interventions for autistic children. Beth happened to see a post on the Me List from someone . . . who was graduating from the Columbia behavioral psychology program, and was beginning to develop programs for people at home. So we contacted her and we met with her. Wonderful, wonderful girl. She decided, fine, she would take over our program. She took over our program for about two years. Then, as she got busier and busier, it was getting harder for her to visit all the houses that she was dealing with. It was about that time that we got a medicaid waiver approved by the DDSO. Once we got that approved, we were able to go to an agency to offer the programming. And that's how we got hooked up with QSAC because they just started offering their services in the Bronx.

So there was about a year when Emily's program at home didn't have any supervision. I mean she was getting the services, but she was getting bored, because she was doing the same things.

S: So the medicaid waiver means that medicaid is picking up the cost for --

M: For our home behavioral services. It also picks up the cost for – Emily is taking certain medications and it also picks up the cost for that. Essentially what the Medicaid waiver does is it gives Medicaid services to the disabled person on the theory that it is the disabled person's resources that they are taking into consideration. Since she has none we are able to waive the other requirements. . . .

S: Is this something that would be available to other families with —

M: Well this is really available to anyone who meets the criteria with a disabled child. The problem here is that it took over two years for us to get that waiver approved. When I say two years, it was two years and the intervention of a State Assemblyman before it was approved. Again, the office was in such disarray, letters were unanswered, telephone calls were unanswered. It shouldn't really take that long. It should take a matter of weeks, not a matter of years. Now the process is a lot better. But, again we're talking about going through this many years ago.

S: When did this Medicaid waiver come through for you?

M: We applied for it, I believe, in 1996 or 1997, and we actually didn't get until 1999 or maybe even a little after that. It was a very long process. But again, it's the way we get Emily's programming at home. Without it, it just wouldn't be possible. Also her medications. One time, it was while the waiver was getting renewed, I needed to renew one of her prescriptions. I brought it to the pharmacy and they said, "Oh, you know your coverage has expired." I said, "It has been approved but we don't have the card." He goes, "I don't know if I can do this again." I said, "Well, I'll tell you what. For this one, I'll just pay for it." He said, "This medication is a little pricey." I said, "What could it be? Sixty, seventy dollars?" A month's supply of – it was Risperidal she was taking – was $770. . . . That's just one of her medications. There is no way I could afford that if we didn't have this. The problem is, she needs it [the medication] because it calms her down and makes it easier for her to go to school and things like that. But these are the other issues that are involved with that as well. That's why it is very important – and we do encourage everybody to explore getting these things, because again, there are times when you just can't survive without it.

S: Emily's current school placement is –

M: Currently she is attending an AHRC program. It's NPS #4. Now because of space considerations, she used to go . . . about 5 minutes away. Unfortunately as the program grew and they needed more space, they had to move the school-age program to another location. So now it's in Brooklyn because that was the biggest building they had. So Emily's program now – I mean it's a little unnerving sending a youngster away to school anyway, but sending a disabled kid. They come and pick her up at about 7:15. I'm told by her teacher that her bus pulls in just about 8:50. So it's a long trip. And there were issues with bus companies along the way as well. Some companies were very good. Some companies were horrible. They wouldn't come pick her up until 10 o'clock, if they would come pick her up at all. I mean I was constantly on the phone with the Office of Pupil Transportation (or something like that), complaining about these things, and just got absolutely nowhere. We're fortunate in that the company that has been taking her to school the last two years has been very, very good. I mean the bus driver is really a nice guy, the matron really is good with the kids. So we've been very fortunate in that. But again, over the years, that has been a problem as well.

S: So CSE is funding her school day, but not any of the extra services.

M: Right. Nothing extra, right.

S: Do you have to go every year to renew that?

M: Well, yah. Because she is in NPS (non-public school) status, the status is good for three years but has to be reviewed once a year. Now we just had her triennial review, so she is going to be in this school for this year, next year, and the year after. The problem that we are having is that the NPS #4 program only goes up to age 12. The problem is that we've got to start looking for some other place to send her. One of the issues that we have to deal with is that there aren't really that many programs here in the Bronx, which is why she is going to Brooklyn. The public programs – there aren't really many of those in the Bronx. I can only think of two . . . There's one in Co-op City which is so saturated they're just not taking people out of district anymore. There's another one that's relatively new – it's about 4 years old. It's called D75 #7. It's a very promising program. It just doesn't have the history yet. The problem with the public school programs though is that they could be a hell of a lot better. The problem is once you get the teachers unions involved, once you get the Board of Ed bureaucracy involved, you lose what needs to be done. You're more concerned with bureaucracy and contracts – I'm not saying that shouldn't be a concern, but I think that when you're talking about kids with special needs, you have to go beyond the box. Unfortunately when you're dealing with big bureaucracies, they don't know "beyond the box," and they don't want to know it. And that's sad because ultimately the kids lose out.

The two programs I just mentioned are okay. They could be better. I'm hearing some good things about D75 #7, but we've got to see. The private schools – the State Education Commissioner, a couple of years back put a moratorium on the expansion of private programs for developmentally disabled kids. Now we happen to think that was a very arbitrary and selfish thing to do, because what they were finding – and this is the lunacy of government education – what they were finding was that more and more people were seeking non-public placement, the reason being because the public placements just weren't meeting the needs of the kids. So, rather than look at the public placements, find out where they were deficient and improve them, what they decided to do was stop the expansion of non-public placements. Therefore, once these programs are full, there's no place to go but the public schools. And that really hurts the kids because nothing was done to improve the public school placements, which were the problem all along.

S: Is this moratorium across the board – does it affect younger children as well?

M: This is education; this is age 3 and on. . . . So the problem is that the AHRC program was approved up to age 12. These kids need it up through age 21. So when your kid hits age 12, it's either look for another place, or home-school them. And the problem is, there just aren't any other places, especially here in the Bronx. The private placements, many of them are Early Intervention programs. Unfortunately we just don't have that many that are for older kids. So the concern that Beth and I have now is trying to find a place — unless AHRC gets the approval to expand – is to find a place where Emily can go after she's 12-years-old. And that's a problem. I know there's NPS #1, but again, do I want to send a 12-year-old disabled kid [that far] every day? There's the Co-op City program which is not taking kids out of district anymore because of the demand. There's D75 #7, but I don't know enough about it. So, those are the concerns we have as far as Emily's future is concerned.

But right now we're pretty pleased with the school she's in. The former principal .

. . retired because she just had a baby. The new principal we're a little wary of because he doesn't have a special ed background. But again, it remains to be seen what's going to go on there. But as far as the staff is concerned, they're very, very good. I have a few issues with some of the social workers there, but other than that the teaching staff is very good. . . [A section in which he describes some frustrating interactions with the school social worker at school]

When she was at SE Preschool #5 . . . the school nurse there I thought was not qualified. Emily found out that if she rubbed her ears, they would take her out of class, bring her to the nurse, and she wouldn't have to do her class work. So any time she had something she didn't want to do, I was constantly getting notes home, "Your child has an ear infection. Your child has an ear infection." And then I get the notes home, "She has an ear infection and we will not accept her back in school unless you've brought her to a doctor and he has certified that she can come back." You know, I take her to a doctor and it's 90 bucks. And she's doing this like three times a month. I can't afford this.

One time she comes home and the matron on the bus says, "Oh I really hope everything works out okay." I said, "What are you talking about?" She goes, "Oh didn't they call you? They said your daughter has ring worm." [End of the side of the cassette tape – he tells about calling the nurse] The nurse says, "We can't take her back unless the doctor certifies she's okay." I'm like, "Where is this infection?" "Oh it's on her right arm." I'm looking at her arm. There's not a scratch on it. I say, "I'm looking at it. There's nothing here." The nurse tells me, "Rather than fight with me I would think you would be more concerned about your daughter's health," and then hangs up on me. What am I going to do? So I take her to the doctor. I tell the doctor and he goes, "Really?" He looks and says, "Where is it?" I'm like, "You're the doctor. You tell me." He looks. There was a little pin prick on her right forearm. It was a mosquito bite. He goes, "Well there's a mosquito bite there, but that's it." So he writes a note: "It's not ring worm. It's an insect bite. There's no need for treatment." I sent the bill into the school. I got an angry call from the principal telling me, who do I think I am, second-guessing their medical professional. I get a call from the nurse saying, who do I think I am. If I every dare do this again, she's going to report me to ACS. I get a call from the social worker there, they would think I would be a little more concerned about my daughter. I'm like, "you people are crazy." Now Emily's head teacher . . . I said to her, "Carol, I don't know what to do. I'm telling you right now. I don't care if Emily has a thousand degree temperature, if she comes near that nurse," I said, "I will sue the whole lot of you. I don't know what for, but I'll think of something." She's like, "Don't worry about it. I have in her thing that if Emily exhibits any sign of sickness, that it come to me, not the nurse." So that's how we handled it.

But I mean these are the things that people don't understand, that you have to deal with. It's not just the autistic child. It's all this other stuff that happens as well. People just don't understand that. Now I must say the nurse at NPS #4 – I can't say enough nice things about her. She will give me a call saying, "Nothing to worry about. I just want you to know Emily got bit by a student. It didn't break the skin, we washed it. Don't even worry about it. But in case you see some irritation, just thought you'd like to know." . . .

S: You said something that a couple of other parents have mentioned – this issue of teachers contracts and a sense of some rigidity. How does that play out in what you've seen?

M: Well – I can't even really generalize to the disabled population, because autistic children are so different. The Board of Ed has determined that in a class of 6 disabled kids, you'll have 1 teacher and 1 aide. That's not enough. That's severely understaffed, because you have 6 kids who don't know how to sit still. So, you have to have one-to-one. But again, that's outside the box. On paper, what they're saying is "Oh we have a 6:1:1 ratio." For a typically developing kid, or maybe for a retarded child or a CP kid that might be okay. But for an autistic child it's simply not enough, because that's 4 kids that don't have anyone on top of them, and they need to have that person. They talk about something called the least restrictive environment. What that means is "least restrictive" for *that* child. It doesn't mean least restrictive in general. So a one-to-one thing, yes, is very restrictive, but for that child, might be "least restrictive" because that child can't function any other way. Home programming is most restrictive because the child is separated from the community at large. But for that child it might be the "least restrictive" because it's the only way the child's going to learn. Therein lies the problem.

Also, you can't schedule a period off. What do you do if one of the kids has a melt-down because they just got overloaded? You can't schedule this period will be free for the teacher. The teacher has to be there all the time. It's just the way it works out. The other thing is you don't teach autistic kids by lecturing. The way you teach a kid how to use a stapler is you put the stapler in their hand, put your hand on top of it and squeeze. Then they have to understand you have to squeeze. Then they have to understand the word "squeeze" means push down. Then they have to understand you wait until the thing goes down. Then they have to understand you pull it back up. Then they have to understand you take the paper away. It's very labor-intensive, it really is. And unfortunately the typical teacher scenario doesn't really account for that. . . .
[Describes other teaching/learning challenges]

S: It's huge.

M: Exactly. You can't do that in a standard teaching situation. So it's very time and labor intensive. I think that's where the typical educational setting and the typical public school teacher contract just doesn't work. You really have to go beyond that, because it's so labor-intensive.
It took us five years to toilet train her. What does it take to toilet train a kid – usually 3, 4, 5 months? It took five years for us to toilet train her, and then she would only urinate in the toilet. She still didn't know that when you move your bowels you do that in the toilet as well. . . . [More about things she is learning and doing at home — and the difficulties involved]

So those are some of the other things that dealing with an autistic child, people don't understand.

S: And when you have other children there's a whole level of complexity.

M: Exactly. Sure. Even people where their autistic child is their only child, don't understand. Beth and I are beyond the stares from people out in public, the nasty comments that people mutter as they see Emily if she happens to be doing something odd.. . . .[Talks about what it is like taking Emily to church]. I've had people tell me that I should consider not bringing my daughter to church because she's very rude. I've had people say, "If you can't control her, keep her home," things like that. We've been at family parties where some of the other kids at the party will make nasty comments about her. I overheard one kid say to another kid at a party once, "Stay away from that girl because she's crazy." It used to bother me. We're used to it now, so we just don't let it bother us. We know it doesn't bother Emily because she doesn't understand what they are saying. It does bother my oldest boy. He gets very upset when he hears people say those things. At one time he almost got into a fight over a comment someone made about Emily. I had to pull him aside, "Ben, it's nice that you want to defend her. It's nice that you think it's not right that people do that. But you have to understand, they don't know what they're saying. So if you want to do something why don't you just tell them, 'This is her problem. This is the situation. You really shouldn't make fun of her.'" But you know, those are other things. . . .[talks about taking Emily to the store, etc.]

S: I have a couple more questions I'd like to ask you. I get the sense that things are improving EI, CPSE.& CSE. What could still make it all work better?

M: What could make it better is more of an open mind on the part of the system. Even though we've come a long way from even seven years ago, there is still an internal prejudice against ABA, against the one-to-one, against really the specialized things that these kids need. It's a lot better than it was. And a lot of that is a result, unfortunately, of litigation. Back in the late 1990's there was a law firm from Pennsylvania that brought a class action suit against New York City Early Intervention, Westchester County Early Intervention, and I believe the State Department of Health, regarding their practices in dealing with autistic children. That law suit – I don't know all the particulars of it, but I think one of the things it did was that it resulted in a consent decree where the government agreed to, at the very least, make known to parents of autistic children that these services were available and that they could access them. They wouldn't even tell us ABA services were available. So at least now it's a little bit better in that they're getting the information out there.

I'm hearing from people that they're starting to offer more in terms of Early Intervention services, as far as full-day programs, as far as behavioral intervention with speech intervention with occupational and physical therapy as well. So, I'm beginning to hear that things are getting a little better.

How can they really improve? I think there still has to be more of an open mind as to what the children need. Now unfortunately it also deals with dollars and cents. These things are very expensive, because there are so few. I think one thing that would help is encouraging students in masters and doctoral programs to pursue these types of things as clinical careers. There just aren't that many people out there. How do you do that? Fund it. I was told by one person that people go into research depending on the grants they can get. There is precious little money out there going into autism research. When you consider it is among the top three, if not the second most prevalent developmental disability among American children these days, it boggles the mind that it is not funded better as far as research goes. But again, squeaky wheels are the ones that get the grease. Unfortunately, other disabilities are much more vocal in their desire for government services and funding. I'm not saying they are not worthy of it. What I'm saying is, I don't think one should suffer because of the other, especially when you're talking about something that happens to – seven years ago, it was determined that 1 in 10,000 children in the United States is autistic. As of maybe three years ago, it's 1 in 500. And it might be even 1 in 250 these days. Whether it's environmental problems, toxins, better diagnosis – doctors are more aware, but even still, the medical community has to open itself up a little more in understanding what is going on. Again, I'm not saying the other things – like juvenile diabetes – aren't worthy of funding and research. What I'm saying is when you have a problem that is this big and that has exploded so much in a very short period of time, I think we really have to start looking at how we can get more funding to discover more things about it. And that's how you are going to get people in it. . . . The question is, "how does that happen?" And unfortunately that's something I just don't have an answer to.

What I do think though is I think the medical community itself needs to be a little more open minded as to possible avenues of inquiry. For the longest period of time there has been this debate over childhood vaccinations and adverse reactions to them . . . [Talks about this, and his concern that not enough careful research has been done in the area]. So I think the medical community needs to keep more of an open mind as to possible causes.

The other thing is that I think the education community really needs to keep an open mind as to how to intervene with these children because classic special ed techniques may not be the thing for the kids. They need something tuned to them. My daughter is autistic. The child next to her is autistic. The two of them have drastically different manifestations of autism. My daughter is severely deficient in her expressive speech. I know autistic children that can converse excellently, but have other issues. Does it mean that one shouldn't get the intervention and the other should? No. They both need it, but they need different things. To say, "We'll put them in the same class, give them the same program," is ridiculous. We were told by Early Intervention – because I asked, "what kind of program are you going to use?" They said, "Oh we'll use one of the published program the Board of Ed recommends. How can you use a published program when you don't know what her individual needs are? I mean are you saying you have a program for every conceivable – I mean, that's ridiculous. I think we have to get beyond that, we really do. Unfortunately, when you're dealing with big bureaucracies like this, the first priority is self preservation, and the way they self-preserve is by putting up all these boxes, and putting this into this box, and that into that box. When you come across the idea that you might need one from this box and one from that box, they don't know what to do with it. Until that whole attitude changes I really don't see things getting much better than they are. . . .

S: Last question: What do you tell new parents who are just coming into this whole process?

M: Well, what I tell new parents #1, is not to be afraid of what is going on. For some reason it is a big shock to hear that word. Parents will hear that their kids have cancer, that their kids have an eyesight problem, that their kids are deaf – they'll take that. But you drop the "autism" word on them and they just go into a whole frenzy. And it's because people just don't know enough about it. So the first thing I tell them is not to be afraid of what's going on.

The second thing I tell them is to ask as many questions as they possibly can, and to read as much as they can about it, and to interact as much as they can with other parents of autistic children. I always invite them to our parent support group. Some of the meetings are very formal – we'll have somebody talk about a particular issue. Other times, we just get together, we chat about what's going on and things like that. The feedback that we're getting is that a lot of people really consider that an important part of their whole dealing with autism issue.

The other things is you really have to make the parents and the caregivers understand that they really are not alone. Because the first thing they feel is isolated. And I understand what they're going through because I felt the same thing. When Beth and I first learned that Emily was autistic, you know, we told people. And you get that, "Yah I understand," but they really don't. And you get the idea that nobody knows what you're going through, nobody understands what you need, and nobody really cares about this particular thing. The thing parents have to understand is that it might take awhile to bring everybody around, but there is a mechanism of people, there *is* a population of people that understand, and you really are not alone. You have to be courageous enough to tap into that. It's easy to withdraw – it really is. And it's very easy to get overwhelmed with these things when you're first starting out. We were fortunate in that we had a good friend who had an autistic child, and we were able to lean on her a lot in the beginning. I am very happy that – and not to pat myself on the back – I am very happy in that we have also been able to have people lean on us as we go on. So I tell them, "come to our support group meetings. You may find it's not for you, but just come and see what goes on. If you have to bring kids, bring them. We know what an autistic kid is like." We've had occasions where people bring their kids and they're constantly saying, "Sh, sh, be quiet, sit down." I'm like, "He's a kid. He's autistic. Don't worry about it. It's not like we've never seen that before." So we do that. But the main thing I tell them is not to be afraid of what is going on and not to feel isolated, because there are people out there who can help them. . . .

I tell people about Emily. We've been dealing with this now seven years. Emily is a different person than she was seven years ago – which I think is good – but she still has a long, long way to go. And for every step forward there were a hundred steps backwards. It's like, you know, "take a giant step forward." Well there are little baby steps forward, and there are a lot of giant steps backward, but it does happen sooner or later.

Also, the other thing I tell parents is, "Don't have too high expectations. Have realistic expectations." The sad fact of the matter is that some children will never communicate – the disability is that severe. Most will, but some may not speak. But, you'll find a way to communicate with your child. Some will have behavioral problems for the rest of their lives. Hopefully yours won't, but some will. Not that I'm telling them, "don't have high hopes for your child," but "try to be realistic." Don't push your child to do more than they can. Because your child is going to resent it and fall back. Let the child take their baby steps and celebrate each one. Then you'll see that you can take bigger and bigger steps. Then you can start having higher and higher expectations. But the first thing they need to do is take those baby steps. Another thing I tell them is, "Yes, there's a lot of grief involved with raising an autistic child, but make sure you celebrate all the successes." That's more important than grieving over the failures. If your success is that today your child picked up the spoon, dunked it in the cereal and then took a bite, celebrate that, because that was their goal for today and that's what they did. And if they do it tomorrow, give the kid extra cereal. . . . Celebrate. When Emily learns something new, "Hey Emily, that's great! That's really great!" She jumps up and down and claps her hands.

S: So she celebrates too.

M: Yah. She does. I've got to say she used to be the most miserable person on earth. She's more happy these days and she's more tuned into what's going on around her. That's good. She has got to be a little more tuned in. And I wish, I really wish she could tell us what's on her mind. But when we started out, she understood nothing. I would say she understands about 70% of what people say to her these days. Before, she didn't have the words. Now when she wants you, she tugs you by the arm and goes, "Come with me," or "Help me," or something like that. Or she'll come in and hold her sock up and say, "Sock on the foot." Seven years ago she would take the sock, look at it, look at it, look at it, and did not know what to do with it. You know, now she picks it up and she tells me, "Sock on the foot." So, it happens. And that's what I tell people. It happens. You've got to wait for it, but it does happen.

Follow-up email correspondence received December 2003:

Does Medicaid pay QSAC for your home ABA therapy?

Actually, QSAC does not pay for ABA therapy but provides residential habilitation (otherwise known as res hab.) Res hab is paid for by Medicaid based on a plan submitted on behalf of each child. The hours of service are based on the needs of the child and the severity of the disability. In the case of QSAC, the agency has trained people to do ABA as part of res hab. In addition to res hab, QSAC provides someone to oversee the program and do in-service training with the day-to-day workers.

I haven't even explored getting OT and speech through Medicaid...I guess that will be next on my list.

Appendix G

Pervasive Developmental Disorders:
Diagnostic Criteria
Abbreviated from DSM-IV-TR (2000)

Autistic Disorder:

A. A total of six or more items from 1), 2), and 3), with:

1) At least two of the following impairments in social interaction:
    - impairment in use of multiple nonverbal behaviors such as facial expression and eye-to-eye gaze, and gestures
    - failure to form developmentally-appropriate peer relationships
    - lack of spontaneous effort to share interests, enjoyment or achievements with other people (eg. lack of showing or pointing out objects of interest)
    - lack of emotional or social reciprocity

2) At least one of the following impairments in communication:
    - delay in or lack of development of spoken language (not accompanied by efforts to compensate through use of gesture or mime)
    - in individuals with speech, marked impairment in ability to initiate or sustain conversations
    - stereotyped and repetitive use of language, or odd language
    - lack of developmentally-appropriate imitative play or spontaneous make-believe play

3) At least one of the following repetitive and stereotyped patterns of behavior, interests or activities:
    - preoccupation with one or more restricted and stereotyped patterns of interest that is abnormal either in focus or intensity
    - inflexible adherence to specific, nonfunctional rituals or routines
    - repetitive and stereotyped motor mannerisms (eg. finger or hand flapping, etc.)
    - persistent fixation with parts of objects

B. Abnormal functioning or delays in at least one of the following areas, with onset prior to age 3 years: 1) social interaction, 2) language as used in social communication, or 3) symbolic or imaginative play.

C. The disturbance is not better explained by Rett's Disorder or Childhood Disintegrative Disease.

Asperger's Disorder

A. At least two of the following impairments in social interaction:
  - impairment in use of multiple nonverbal behaviors such as facial expression and eye-to-eye gaze, and gestures
  - failure to form developmentally-appropriate peer relationships
  - lack of spontaneous effort to share interests, enjoyment or achievements with other people (eg. lack of showing or pointing out objects of interest)
  - lack of emotional or social reciprocity

B. At least one of the following repetitive and stereotyped patterns of behavior, interests or activities:
  - preoccupation with one or more restricted and stereotyped patterns of interest that is abnormal either in focus or intensity
  - inflexible adherence to specific, nonfunctional rituals or routines
  - repetitive and stereotyped motor mannerisms (eg. finger or hand flapping, etc.)
  - persistent fixation with parts of objects

C. The disturbance causes significant impairment in social, occupational, or other important areas of functioning

D. There is no significant delay in language acquisition (eg. single words used by age 2, etc.)

E. There is no significant delay in cognitive development, acquisition of appropriate self-help skills, and curiosity about the environment

Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)

This category is used when there is severe and pervasive impairment in the development of "reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behavior, interests, and activities, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder. For example, this category includes 'atypical autism' – presentations that do not meet the criteria for Autistic Disorder because of late age at onset, atypical symptomatology, or sub-threshold symptomatology, or all of these" (DSM-IV-TR, p.64).

Rett's Disorder

A. All of the following:
  - normal prenatal and perinatal development
  - normal psychomotor development through the first 5 months of life
  - normal head circumference at birth

B. Onset of all of the following after the period of normal development:
  - deceleration of head growth between 5 and 48 months of age
  - loss of previously acquired purposeful hand skills between 5 and 30 months of age, with development of stereotyped hand movements (eg. hand-wringing, etc.)
  - loss of social engagement (although social interaction often develops later)
  - appearance of poorly coordinated trunk movements or gait
  - severely impaired receptive and expressive language development, and severe psychomotor retardation

Childhood Disintegrative Disorder

A. Apparently normal development for at least the first 2 years of life (with age-appropriate verbal and nonverbal communication, social relationships, adaptive behavior and play)

B. Significant loss of previously acquired skills before age 10 in at least two of the following areas:
  - receptive or expressive language
  - social skills or adaptive behavior
  - bowel or bladder control
  - play
  - motor skills

C. Abnormal functioning in at least two of the following areas:
  - impairment in social interaction (eg. non-verbal behaviors, peer relationships, etc.)
  - impairments in communication (eg. delay or lack of spoken language, inability to initiate or sustain a conversation, lack of make-believe play, stereotyped and repetitive use of language)
  - repetitive, stereotyped patterns of behaviors, interests and activities

D. The disturbance is not better explained by another PDD or by Schizophrenia.

Appendix H

October 2003

Hello

I am a social work and early childhood special education student at Columbia University and Bank Street College. I've been interested in following the changes going on in the public schools over the last several years. However, especially with regards to special education, I have wondered how these changes are affecting individual children and their families. How well are the new policies and programs working?

To begin to answer these questions, I am looking for parents of children with autism spectrum disorders, who would be willing to talk with me about their child's educational experiences. I especially hope to visit with parents of elementary school-age children who either are or have been in New York City public schools.

If you are willing to participate, I will schedule an appointment to meet with you for 1-2 hours in the next several weeks. The focus of our conversation will be your child's education-related experiences and your assessment of these.

I will be writing a paper based on these interviews, which I will be happy to share with you. In addition, I will insure the confidentiality of all who participate.

If you are willing to be interviewed, or if you would like more information, please contact me at: [email address]. Alternately, you can call me at [phone number].

Thank you!

Suzy Jensen

Appendix I

INFORMED CONSENT

Bank Street College of Education
Graduate School
(212) 875-4400

I am currently working on a research project that will study how parents view the special education experiences of their children. In particular, I am focusing of the experiences of children with autism spectrum disorders. The purpose of the research is to explore parents' perspectives about current services, placements and programs, and to learn which of these are most effective for their children.

The project includes audio taping a person-to-person interview for purposes of transcription and evaluation. This tape will be destroyed upon completion of the project.

In order to ensure complete confidentiality, no identifying information about you, your child or you child's school will be included in my final paper. At your request, I will be happy to provide you with a copy of the paper.

If at any point you wish to withdraw from this project, it is your right to do so.
Thank you for your participation.

____
Name

____
Signature

____
Date

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Thank you for your participation.

Julius DiFiore
Name

Signature

11/4/03
Date

INFORMED CONSENT

Bank Street College of Education
Graduate School
(212) 875-4400

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Thank you for your participation.

DIANE PERUGGIA
Name

Diane Peruggia
Signature

10-1-03
Date

Informed Consent

Bank Street College of Education
Graduate School
(212) 875-4400

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Thank you for your participation.

Lynn K. Decker
Name

Lynn K. Decker
Signature

October 15, 2003
Date

INFORMED CONSENT

Bank Street College of Education
Graduate School
(212) 875-4400

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If at any point you wish to withdraw from this project, it is your right to do so.
Thank you for your participation.

Linda Halbtuch
Name

Signature

Oct 28, 2003
Date

INFORMED CONSENT

Bank Street College of Education
Graduate School
(212) 875-4400

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If at any point you wish to withdraw from this project, it is your right to do so.
Thank you for your participation.

Beth [illegible]
Name

Beth Rosenberg
Signature

11/3/03
Date

INFORMED CONSENT

Bank Street College of Education
Graduate School
(212) 875-4400

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If at any point you wish to withdraw from this project, it is your right to do so.
Thank you for your participation.

Christine Vilart-Bass
Name

Signature

11/3/03
Date