

**Students with Autism Spectrum Disorders in New York City:
An Assessment of Current Special Education Service Delivery**

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Advocates for Children

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Executive Summary

The number of children diagnosed with Autism Spectrum Disorders (ASD) has been growing rapidly over the past several decades. This has an enormous impact on school systems, which must provide appropriate educational services to children diagnosed with ASD. In New York City there appears to be a dearth of appropriate placements and properly trained assessment professionals and teachers to serve children with these disorders. While the majority of children classified as autistic in the special education system in New York City are minorities, most of the children who are placed in higher quality private schools are white. Poor children and children of color with ASDs are more often placed in public special education classrooms that are ill-equipped to meet their special needs. In addition, they are oftentimes mis-diagnosed or not identified until the child is of school age. A lifetime of dependency is too often the outcome of inadequate and inappropriate schooling for these; three quarters of Americans who have autism or who have disorders on the autism spectrum spend their lives in institutions or group homes, at public expense.¹

This report was undertaken by Advocates for Children of New York (AFC) for the purposes of conducting an assessment of the manner in which special education services are delivered children in New York City who are diagnosed with Autism Spectrum Disorders (ASDs), with a particular focus on the delivery of services to poor children of color.

Our general conclusions are as follows:

- Children are mis-diagnosed or not identified until they are school age and assessment professionals do not have the skills to understand the needs of children with ASD.
- The procedural requirements of the federal Individuals with Disabilities and Education Act (IDEA) are being flouted, resulting in Individualized Education Plans (IEPs) and program recommendations that are wholly inadequate and in violation of the law.
- The quality of the services and programs offered by the public schools to children with ASDs need improvement and do not incorporate the use of research-based methodologies in order to provide adequate treatment to children with ASDs.
- Educators and staff working with children with ASD lack the appropriate skills and training needed to work with this population.
- Poor parents of color have virtually no information about the special education system or ASD, which hampers their ability to ensure that their children are identified early enough and provided better quality services

¹ *Developing a Solution to the Current Crisis in the Education of Children with Autism*, A Proposal to the New York State Legislature by the Autism Coalition of the Empire State, June 11, 2000.

through the special education system.

- Poor parents of color do not have sufficient access to legal assistance or medical professionals who can identify the signs of children with ASD and make appropriate referrals.

The report begins with an overview of the federal laws governing special education services and then examines some of the available data on autism and its prevalence nationally, statewide and in New York City. A discussion of the growing rate of autism and its possible explanations is included. It then provides an overview of the consensus among experts regarding the assessment and effective treatment of children with ASDs. The report then discusses services in New York and summarizes ten of AFC's own cases involving students with autism and autism spectrum disorders. Following these synopses, certain problem areas in the provision of services to this population are highlighted and supplemented by interviews with advocates and service providers. It finally discusses the methods in which legal advocacy can be used to effectuate individual and systemic remedies. At the end of the report, we set out three suggested steps toward an action plan for reform, which include expansion of individual representation for families of children with ASD, parent training and organizing and public policy advocacy.

I. IDEA-The Framework of the Special Education Service Delivery System

We start the report with a description of the Individuals with Disabilities Education Act (IDEA)—the federal law that governs the delivery of special education services to children with disabilities. This overview provides a context for the discussion of whether these children’s rights to educational services are being violated.

Congress enacted the IDEA to ensure that children with disabilities have meaningful access to public education. States which receive funding through the IDEA receive these substantial federal funds in exchange for their agreement to provide a free appropriate public education to all disabled children in the state, and to comply with the IDEA’s procedural and substantive mandates. The IDEA provides that every student (birth to 21) must be provided with a free and appropriate public education. Eligible children are entitled to be educated in the least restrictive environment – which means with their non-disabled peers, to the maximum extent appropriate.

Eligible students are entitled to special education, related services and supplementary aids and supports. The law defines “special education” as instruction specifically designed to meet the unique needs of a child with a disability.² “Related Services” are to be provided if children need them to benefit from special education. They include services such as transportation to and from school, speech-language pathology services, psychological services, physical and occupational therapy, counseling services, medical services for diagnostic or evaluation purpose, school health services, social work services and parent counseling and training.³ If necessary, students are entitled to assistive technology. All students over the age of 14 must also be provided

² 34 CFR § 300.26 (Special Education).

³ 34 CFR § 300.24 (Related Services).

“transition services” to enable them to transition to post-secondary education, employment or independent living.

The IDEA also requires that the state and local districts provide an adequate supply of properly trained staff to meet the needs of the special education population it serves.⁴ The provision of special education services must use proven methods of teaching and learning and must be based on replicable research.

There are, generally speaking, three types of services that must be provided to children with disabilities. They are services for early intervention (children from 0-3 years), pre-school services (3-5 years) and school-age (5-21 years). The law further requires that each state must have in effect policies and procedures to ensure that all children with disabilities residing in the state who are in need of special education and related services, are identified, located, and evaluated.⁵ These policies must be sufficient to ensure that outreach efforts are being made to locate these children. Such efforts could include hospitals and day care providers, as well as the more traditional means of identifying disabilities in school. A referral for intervention for a child identified as having a disability and being in need of services can be made by anyone and the state is then required to conduct an evaluation of that child in order to assess his or her specific needs. Children who are not referred for an evaluation before they are of school age should receive an evaluation and placement recommendation when they are five, and entering the public school system.⁶ At whatever time during a child’s life she or he is evaluated, all areas of the suspected disability must be assessed. A child is eligible for

⁴ 34 CFR §§ 300.380-382.

⁵ 34 CFR § 300.125 (Child Find).

⁶ In New York City, when a child turns five, s/he is evaluated and recommended for a placement by the Committee on Special Education (CSE).

special education services if she or he is found to have one of thirteen disabling conditions, one of which is autism.

The law provides that children with disabilities be evaluated pursuant to certain minimum standards. Among these are requirements that:

- Tests are selected and administered so as not to be discriminatory on a racial or cultural basis; and are provided and administered in the child's native language or other mode of communication.
- A variety of assessment tools and strategies are used to gather relevant functional and developmental information about the child, including information provided by the parent.
- Tests are selected and administered so as best to ensure that if a test is administered to a child with impaired sensory, manual, or speaking skills, the test results accurately reflect the child's aptitude or achievement level.
- Tests and other evaluation materials include those tailored to assess specific areas of educational need.
- The child is assessed in all areas related to the suspected disability.
- The evaluation is sufficiently comprehensive to identify all of the child's special education and related services needs.⁷

A parent is entitled to obtain an evaluation of his or her child independent of the one provided by the local educational agency, in this case the New York City Department of Education (DOE). This evaluation can be obtained at public expense if the parent disagrees with the outcome of the evaluation performed by the public school system.⁸ The law further provides that all special education students must be re-evaluated at least triennially.⁹

Once a child is evaluated and found to have a disability, an Individualized Education Plan (IEP) must be developed for that child. The law requires that a team of

⁷ 34 CFR § 300.532.

⁸ 34 CFR § 300.502.

⁹ 34 CFR § 300.536.

individuals be present in order to develop the child's IEP and that this group include the child's parent(s), a regular education and a special education teacher of the child, a representative of the local school district, and an individual who can interpret the instructional implications of evaluation results.¹⁰ In developing an IEP, the team must consider a number of issues. These include the strengths and weaknesses of the child and the concerns of the parents for enhancing the education of their child, as well as the results of the most recent evaluation of the child. This team of individuals must further consider strategies, including positive behavioral interventions, to address problem behavior. The team must also consider the communication needs of the child and whether the child requires assistive technology devices and services.¹¹

The IEP itself must meet certain legal requirements. The IEP for each child with a disability must include a statement of the child's present levels of educational performance, a statement of measurable annual goals, including benchmarks or short-term objectives, and a plan for service provision in order to meet the child's needs and to enable the child to advance toward attaining these goals. It must further indicate how the child will be assessed, how the services the child needs will be delivered, how the child's progress toward his or her goals will be measured, and how the child's parents will be informed of their child's progress.¹² The IEP must be implemented in its entirety. According to the law, the services specified in the child's IEP must be provided.¹³ Each special education student's IEP must be reviewed annually.¹⁴

¹⁰ 34 CFR § 300.344.

¹¹ 34 CFR § 300.346.

¹² 34 CFR § 300.347 (Content of IEP).

¹³ 34 CFR §§ 300.347; 300.350. In New York City, when a child is placed in a classroom that is not serving his needs in accordance with his IEP, the parent has the right to request that the placement be modified. If the parent feels that the child's needs cannot be met in the public schools, the parent may obtain a private placement for the child and seek reimbursement from the NYC DOE. Alternatively, if the

In order to ensure that children are receiving their legally mandated educational services and the parents have meaningful opportunities to participate in the special education process, the IDEA guarantees children and their parents numerous procedural safeguards. These include but are not limited to (1) the right to receive notice every time the district proposes to evaluate a child or change a child's placement; (2) the right to consent to any evaluation conducted; (3) the right to raise complaints concerning the referral, evaluation, IEP, placement or Free and Appropriate Public Education (FAPE) through mediation or an administrative hearing and appeal; (4) the right not to be denied services for more than ten days in any given year; (5) the right to a private evaluation paid for by the district if the parent disagrees with the district's evaluation; (6) the right to receive notice of all rights and safeguards.

In addition, the IDEA contains a complaint procedure whereby parents can file letter complaints with the state educational agency concerning violations of their children's rights or illegal district policies. In addition, another law, Section 504 of the Rehabilitation Act, allows parents to lodge complaints concerning their children's educational program with the federal Department of Education.

Parents are also able to seek relief in federal or state court to redress illegal actions taken by school districts or states. However, in general, they must use the IDEA's administrative hearing process first, before they can file a case in court.

NYC DOE agrees that the child is not in an appropriate placement and that the NYC DOE does not have an appropriate placement available, the child can be placed privately, at public expense, at the initiative of the NYC DOE.

¹⁴ 34 CFR § 300.343.

Unfortunately, the federal framework for service delivery, while mandated, is far from being implemented in New York City for parents of children with ASD.

II. Autism Data

A. The National Profile

Autism and disorders on the Autism Spectrum (referred to as “ASD” in this report) are complex and severe developmental disorders that affect a person's ability to communicate, form relationships with others, and respond appropriately to the environment. Those affected may avoid making eye contact and lack the ability to read faces for signs of emotion or other cues. Children with ASDs typically do not engage in social play or games with their peers. Unusual behaviors such as rocking, hand-flapping or even self-injurious behavior may be present in some cases. Individuals with ASDs have unusual social, communicative and behavioral development and may have abnormalities in cognitive functioning, learning, attention and sensory processing.

Understanding of autism has grown tremendously since it was first described by Dr. Leo Kanner in 1943. *The American Psychiatric Association Diagnostic and Statistical Manual: Fourth Edition, Text Revised (DSM-IV-TR)* provides the most recent diagnostic criteria. Until 1994, autism was classified as a disorder without reference to pervasive developmental disorders. Autism is currently viewed as a spectrum disorder that is under the rubric of pervasive developmental disorders, which includes disorders that cause severe deficits early in a child's development. Pervasive Developmental Disorders include (a) Autistic Disorder, (b) Rett's Disorder, (c) Childhood Disintegrative

Disorder, (d) Asperger's Disorder, and (e) Pervasive Developmental Disorder not Otherwise Specified (including Atypical Autism).¹⁵

There has been a significant and rapid rise in the number of children who are identified with disorders on the autism spectrum. The rate of children diagnosed with ASD is growing at a rate of more than 20% per year, according to the U.S. Department of Health. Autism crosses all racial and ethnic boundaries. However, gender differences do appear in the research; three out of every four people with autism are male.

Currently, the exact number of people with autism in the United States is not known, but estimates range from one-in-500 births to one-in-1000 births. This contrasts with studies conducted in the 1960s that pointed to 4-5 people with autism among 10,000 people, which is why autism was once thought of as a rare condition.¹⁶ Many surveys conducted in the 1960s and 1970s only dealt with autism disorder (as opposed to ASD) and with a narrow definition of autism.¹⁷ Thus, comparisons or rates over time generally deal with studies that have used different case definitions, making interpretation of time trends difficult. The closest estimate of ASD prevalence available in the late 1970s was 20 per 10,000 in a survey from the U.K. that was limited to the severely impaired children with ASD.¹⁸ Rates of autism disorder in recent surveys have consistently been more than 10 per 10,000 whereas previous prevalence estimates ranged from 4 to 5 in 10,000.¹⁹ From the available evidence it can be concluded that recent rates for both ASD

¹⁵ It is called a developmental disability because it starts before age three. [See National Institute of Child Health and Human Development: www.nichd.nih.gov].

¹⁶ According to Saunders & Jesinkey,, the rate of autistic-type disorders in children has dramatically increased from 5 in 10,000 births to a rate possibly as high as 1 in 500 births (*Autism Research Review International*. Evidence mounts for epidemic of autism. Quarterly publication of the Autism Research Institute, Vol. 14, (2), pp. 1-2.

¹⁷ See, e.g., Kanner L. "Autistic disturbances of affective contact." *Nervous Child*. 1943;2:217-250.

¹⁸ Wing L, Gould J. "Severe impairments of social interactions and associated abnormalities in children: epidemiology and classification." *J Autism Dev Disord*. March 9, 1979:11-29.

¹⁹ Fombonne E. "Epidemiological trends in rates of autism." *Mol Psychiatry*. 2002; 7(suppl 2); S4-S6.

and Autism disorder are 3 to 4 times higher than 30 years ago.²⁰ National data indicates that the number of school-age children classified as autistic jumped from 22,664 students in the 1994-95 school year to 97,904 students in school year 2001-2002.²¹

Annexed to this report, as Exhibit 1, is a report issued by the United States Department of Education that displays the numbers of children served in the United States under the IDEA, by disability category, including autism. A review of this data reveals that the numbers of children classified as autistic under the IDEA has risen over the past decade and at a rate disproportionate to that of other disability classifications.

There are several possible interpretations of this increase in prevalence. The increase almost certainly reflects a broadening of the concept of ASD with more inclusive diagnostic criteria and improved methods of case finding in population surveys; it is generally agreed that the definition of autism has been broadened over the last few decades, particularly at the less severe end of the spectrum. These major changes in autistic classification occurred from the *Diagnostic and Statistical Manual of Mental Disorders, Third Edition (DSM III)* in 1980 to the *DSM-Revised Third Edition* in 1987 and the *DSM, Fourth Edition* in 1994. Kanner's infantile autism was replaced in 1980 with the concept of pervasive developmental disorder. Among the pervasive developmental disorders, pervasive developmental disorder-not otherwise specified (PDD-NOS) has now become the most widely used ASD diagnosis, and Asperger disorder emerged as a new diagnostic category in the 1990s.²²

²⁰ Fombonne, E. JAMA editorial on the prevalence of autism, 1/1/03.

²¹ United States Department of Education, Office of Special Education Programs, Data Analysis System.

²² Id. It has been suggested that the Individuals with Disabilities Education Act, mandating that states provide early intervention programs for toddlers with developmental delays, played a role in the increasing use of the diagnosis of autism. Croen LA, Grether JK, Hoogstrate J, Selvin S. "The changing prevalence of autism in California". *J Autism Dev Disord.* 220: 32:207-215.

In sum, there is solid evidence to support that higher prevalence rates reflect changes in diagnostic practices, improved identification and availability of services. However, the additional possibility of an increase in the incidence of autism cannot be ruled out. Although evidence is currently weak that environmental contaminants or exposures account for the increase, a substantial research effort is underway in this country to test these hypotheses.²³

B. Profile of New York State

As with national trends, there has also been an increase in the number of children diagnosed with autism spectrum disorders in New York State, as demonstrated through the classification of children through the special education system. The rate at which children are being diagnosed as autistic in New York State has doubled from 3,113 in 1995-1996 to 7,023 in 2001-2002. A significant increase was seen in the school-age population of 6-11 year olds; classification of children in that age rose from 1,632 in '95-96 to 4,637 in '01-02.

The following table depicts the numbers of students in New York State served under the IDEA who were classified as autistic as compared to the total numbers of disabled students, over a period of several years.

²³ *New York Times*, 10/18/02, article by Sandra Blakeslee "Increase in Autism Baffles Scientists" describes findings from a California study conducted by Dr. Robert Byrd and colleagues at the University of California at Davis. The study found that genetics, birth injuries, and childhood immunizations did not explain the increase in childhood autism in California in recent years.

Number of Students in New York State Served Under the IDEA

School year	6-11 year olds			12-17 year olds		
	Total with disabilities	Total classified autistic	Percent classified autistic	Total with disabilities	Total classified autistic	Percent classified autistic
1995-1996	158,300	1,632	1.03	164,844	1,047	.64
1996-1997	168,989	1,780	1.05	170,903	911	.53
1997-1998	173,801	2,189	1.26	175,124	998	.57
1998-1999	176,431	2,751	1.56	181,245	1,472	.81
1999-2000	175,003	3,267	1.87	185,435	1,344	.72
2000-2001	174,431	3,987	2.29	189,638	1,580	.83
2001-2002	169,343	4,637	2.71	195,632	1,965	1.00

School year	18-21 year olds			Total		
	Total with disabilities	Total classified autistic	Percent classified autistic	Total with disabilities	Total classified autistic	Percent classified autistic
1995-1996	23,161	434	1.87	346,305	3,113	.90
1996-1997	23,193	278	1.20	363,085	2,969	.82
1997-1998	24,077	279	1.16	373,002	3,466	.93
1998-1999	23,827	316	1.33	381,503	4,539	1.19
1999-2000	23,769	340	1.43	384,207	4,951	1.29
2000-2001	22,773	376	1.65	386,842	5,943	1.54
2001-2002	21,944	421	1.92	386,919	7,023	1.82

Source: United States Department of Education Annual Reports to Congress on the Implementation of the Individuals with Disabilities Education Act Preschool Data

The growing concern about the increasing numbers of children with autism prompted the New York State Legislature to pass Chapter 405 of the Laws of 1999. Chapter 405 directed the New York State Education Department (SED) to conduct “*an assessment of the availability and effectiveness of approved programs providing services to preschool children with autism.*” Interestingly, this law only focused on preschoolers

and did not require an evaluation of programs for school-age children.²⁴ SED, in turn, asked the New York Autism Network (NYAN) to conduct a study examining these issues. The study was initiated in December 2000 and data was collected between June 2001 and March 2002. Surveys were distributed to and received from three different sources:

- (1) Directors of State-approved preschool programs (n = 307),
- (2) Chairpersons of Committees on Preschool Special Education (CPSEs) (n = 609), and
- (3) Parents of children with autism (n = 383).

The surveys asked a number of questions on the availability of programs and services for children with ASDs, as well as components of effective instruction and outcomes. The term *preschooler with autism* was derived from current diagnostic manuals and the Part 200 Regulations:

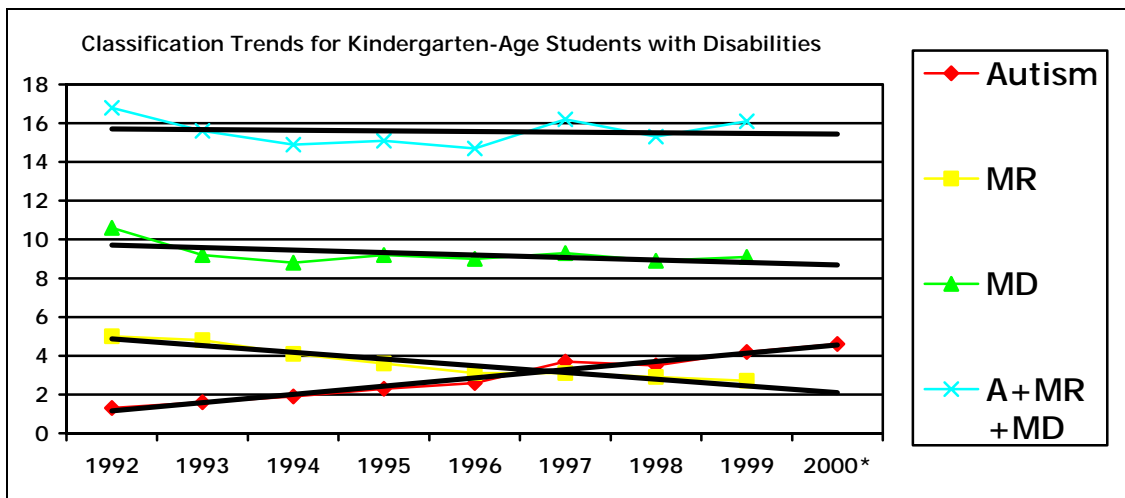
A child having a developmental disability affecting verbal and nonverbal communication and social interaction; who may have behavioral characteristics associated with autism, such as engagement in repetitive activities and stereotyped movements, resistance to environmental change or changes in daily routines, and unusual responses to sensory experiences; and who is likely to be classified as having autism upon reaching school age.

Both program directors and CPSE chairs reported large increases in the number of children with autism relative to historical levels.²⁵ NYAN also examined the number of

²⁴ SED, however, recently requested applications for “*Effective Instructional Programs for School Age Students with Autism*.” Eden II is among the 10 programs selected for a site visit. Successful applicants will be awarded grants to assist other schools to replicate effective programs and practices.

²⁵ The report has not yet been published. CPSE chairpersons estimated that 5.6% of the children they serve have ASD. Program directors estimated that 10.7% of the children they serve are on the autism spectrum. This discrepancy might be explained, in part, by the fact that CPSEs are responsible for a much larger number of children and a broader cross section of children; they also reported their results for the entire year compared to a single day. Program directors, on the other hand, may be sensitive to more subtle manifestations of autism, which might make them more likely to describe their students as having autism.

kindergarten-age children classified as having autism in New York State between 1992 and 1999. According the Executive Report to NYSED, this number has shown a steady upward trend in both number and proportion from 110 students (1.3% of children with disabilities) in 1992 to 727 (4.2%) in 1999, with a projected rate of 4.6% and approximately 815 students for 2000, if the eight-year trend is maintained. This trend is displayed in the figure below. For comparison purposes, this figure also provides data for students classified as having mental retardation and those having multiple disabilities, both of which have shown downward trends in the same time period.²⁶ It is interesting to note that the growth in the school-age figures has not matched the projections of Crimmons, et al.



Source: Executive Report to NYSED

The report also documents regional differences, with higher percentages in the eastern and southeastern regions and lower proportions of preschool children with autism in the central and western regions of the state. New York City, for example, accounts for 39% of all school-age special education students served in the state while more than 70% of all students with ASD in New York State are from New York City.

²⁶ Interestingly, the sum of these three classifications has remained relatively flat at just under 16%, ranging between 14.7 and 16.8% during this time, which may suggest movement across the classifications rather than an “epidemic” of new cases of significant developmental disabilities in kindergarten age children. Crimmins, D. B., Durand, V. M., Rafferty, Y., & Kaufman, K. (2003). *Report on the Availability and Effectiveness of Programs for Children with Autism in New York State*. Valhalla, NY: Westchester Institute for Human Development at Westchester Medical Center.

C. Profile of New York City

According to the most recent reports that the New York City Department of Education submitted to SED pursuant to their IDEA obligations to report data, there are 3,556 children in New York City receiving special education services who are classified as having autism. The ethnic/racial breakdown is as follows: 1,361 of the children are Black, 1,056 are Latino, 831 are White, 271 are Asian, and 37 are American Indian/Alaskan native.²⁷ The gender ratios found in the national research are replicated in New York City, where approximately 75% of autistic students are male.²⁸ The table below indicates the numbers of children in the New York City public schools who have been given the classification of autistic, as compared to the total number of students being served under the IDEA. These numbers and growth rates approximate those found at the state level although they do not reach the levels one would expect based on the national numbers and research in the field.

Numbers of Children with Autism Classification in New York City Public Schools

As of December of	Number of disabled students	Number of disabled students classified autistic	Percent of disabled students classified autistic
1997	137,527	1,756	1.28%
1998	147,674	2,291	1.55%
1999	146,949	2,621	1.78%
2000	149,332	2,947	1.97%
2001	146,328	3,278	2.24%

Source: PD-1/4 Reports to New York State Education Department

²⁷ As of December, 2002.

²⁸ According to CAP Registers, District 75 Enrollment by Disability, Race and Gender.

The tables below depict the numbers of children with an autism diagnosis in the New York City public school database in December of 2000, 2001, and 2002. These numbers are broken down to show the number and percentage of all autism diagnoses by race.

Number of Children with Autistic Diagnosis in NYC Public School Database

Autistic	American Indian/ Alaska Native	Asian or Pacific Islander	Black (Not Hispanic)	Hispanic	White (Non-Hispanic)	Total
Dec-00	33	240	1,174	848	652	2,947
Dec-01	36	256	1,275	945	766	3,278
Dec-02	37	271	1,361	1,056	831	3,556

Source: PD-1/4 Reports to New York State Education Department

Percent by Ethnicity of Children with Autistic Diagnosis in NYC Public School Database

Autistic	American Indian/ Alaska Native	Asian or Pacific Islander	Black (Not Hispanic)	Hispanic	White (Non-Hispanic)	Total
Dec-00	1.1%	8.1%	39.8%	28.8%	22.1%	100.00%
Dec-01	1.1%	7.8%	38.9%	28.8%	23.4%	100.00%
Dec-02	1.0%	7.6%	38.3%	29.7%	23.4%	100.00%

Source: PD-1/4 Reports to New York State Education Department

The table below indicates the number of autistic children who were 5, 6 and 7 years old at the time they were diagnosed. Of the 1,053 children diagnosed between 5 and 7 years of age, 316 came into the system as a five year old with a diagnosis of autism, 11 were diagnosed during their kindergarten year by the CSE, 386 were diagnosed during their first grade year by the CSE and 340 were diagnosed during their second grade year by the CSE. This data indicates that the majority of these children were not diagnosed until they were of school age. As early diagnosis of this disorder is

critical to its successful treatment, this observation is troubling. Moreover, it indicates that there may be deficiencies within the public school system in identifying the disorder.²⁹

Age at Diagnosis of Selected New York City Autistic Children

ETHNICITY						
GRADE	American Indian	Asian/Pacific	Hispanic	Black	White	TOTAL
Turn 5	0	24	90	99	103	316
Kindergarten	0	2	5	2	2	11
1 st Grade	1	22	113	131	119	386
2 nd Grade	1	32	112	106	89	340
TOTAL	2	80	320	338	313	1053

Source: New York City Department of Education Summary of Autistic Children aged 5, 6 & 7 as of December 2002

D. The Role of Race in Special Education Placement

For more than 30 years the United States Department of Education as a whole, and their Office of Civil Rights in particular, have found that ethnic minority students are over-represented in the public school special education population. Specifically, African-American and Latino students are about twice as likely as white students to be educated in a restrictive, substantially separate education setting.³⁰

When AFC started this research, our goal was to empirically document the racial disparities in terms of placement of children with ASD in private schools. Unfortunately,

²⁹ As discussed further below, assessment professionals may not be properly trained on diagnosing ASD.

³⁰ *Racial Inequity in Public Education*. Edited by Daniel J. Losen and Gary Orfield. Harvard Education Press, Cambridge, MA. [800-513-0763].

although AFC attempted to obtain data from the State Department of Education with regard to race disparities in the placement of autistic students, the State was not forthcoming with this information. Due to the relatively small numbers of children classified as autistic, and the even smaller numbers once broken down by race, the State argued that it was not permitted to reveal this information, as individual children's identities could be ascertained from the data.³¹

It does appear, however, from data received from the State that white children with disabilities are over-represented in private special education facilities as compared with their black or Hispanic counterparts. In New York City, white students are far more likely to attend private special education schools at public expense. As of December 1, 2000, of all students with disabilities placed in separate settings (i.e. buildings attended by students with disabilities only), 50% of white students were placed privately as compared with 21-22% of black and Hispanic students.³² It is reasonable to assume that the breakdown is similar for autistic students. Moreover, while approximately 15% of the special education student population is white (which mirrors their representation in the public school system), white students account for approximately 38% of private placements in a day school and 36% of placements in private residential programs.³³

Moreover, it appears from conversations with parents, advocates and specialists in the field that private programs for autistic children are overwhelmingly populated by white students. An inquiry as to why this is the case elicited remarkably consistent responses from the individuals entrenched in the field.

³¹ Whether this argument was a spurious one, intended only to keep the data from the public is a separate question, which will not be dealt with here.

³² PD4, 2000-2001, Section C(15), Table 2.

³³ Id. compare with PD.

- “It is a socioeconomic issue. Poor parents and single parents don’t have the means to do this.”³⁴
- “Knowledgeable parents want their children in private schools. Many White parents get lawyers. Black children are more likely to be in public school programs.”³⁵
- “There is no racial bias. The problem is parental education. The Committees on Special Education are not telling parents about their options. There is an ignorance problem. Parents are not educated about their options. Teach parents to be advocates for their children.”³⁶
- “While children of color are under-represented in private schools, I think this is because their parents have fewer resources available to them. The children who are in private schools are there because their parents are knowledgeable and they have the resources. They fight for their kid’s placements in high quality private programs. Minority students tend to be poorer; their parents are less educated and they do not have the same kind of resources available to them.”³⁷

This issue of racial disparities in placement needs to be examined further. However, it is evident that parents with financial means have much greater access than their less well-off counterparts to services and advocacy tools to obtain private placements.³⁸

III. Best Practices

A. Early Intervention and Assessments

The American Academy of Neurology (AAN) has recommended that all children be routinely screened for developmental problems, specifically autism, starting from infancy. The AAN recommends regular developmental screenings during all pediatrician checkups from infancy through school age, and at any later stage if problems with social interactions, language, learning or behavior are detected. It is estimated that currently

³⁴ Lisa Veglia, QSAC.

³⁵ Janice Silber, Advocates for Children.

³⁶ Andrew Bauman, ACES.

³⁷ Janice Silber, AFC.

³⁸ This observation dovetails with the fact that children born to parents with means appear to have a better chance of being diagnosed early with autism, hence increasing their chances of being successfully treated.

fewer than 30 percent of children receive developmental screening at these appointments.³⁹ If risk factors, such as the failure to meet childhood milestones, or a sibling with autism, are detected, further developmental evaluation is required.

There appears to be consensus that the earlier autism is diagnosed, the better the educational outcomes for children receiving appropriate treatment. Ideally, a child suffering from ASD should be diagnosed at age two. Failing that, a diagnosis by the age of three or four years is critical. If a child goes undiagnosed until the age of six or seven, it is possible that irreparable damage will have been done.⁴⁰ Of course, behavioral and other interventions may always prove useful in improving an autistic child's functioning, even if irreparable harm has already been suffered.⁴¹ When parents, specialists and educators are aware of a child's disability from the start, they can intervene early by building stimulating learning environments that allow the child to later function at a higher level. When developmental disabilities are not detected, children miss out on these growth opportunities. There is a great deal of evidence that when one provides a child with the best possible learning environments in early developmental years it will have a long-term positive impact.⁴²

In the event that a child is not properly diagnosed with an ASD until he or she is older, the disability requires immediate attention. Many ASD sufferers display high functioning in areas of word recognition, communicative speech and reading decoding. These may lead teachers and parents to believe that a student with autism has successfully displayed mastery of core subject knowledge. Often that determination is

³⁹ *Best Practices for Educating Students With Autism*, LRP publication (2001).

⁴⁰ Dorothy Siegel, NYU Institute for Education and Social Policy.

⁴¹ Joanne Buccellato, parent and AFC advocate.

⁴² Marilou Hyson, associate director at the National Association for the Education of Young Children.

wrong. While autistic students sometimes exhibit high levels of engagement in procedural knowledge skills, many are not fully comprehending subject matter necessary for later success, especially once teachers raise expectations based on age levels.

According to autism experts, students with ASDs may well look for ways to get out of situations when they find themselves ill-prepared to understand skills like reading comprehension, inferential reasoning and synthesizing information (and these areas of expectation begin as early as grade three). In order to avoid this, school professionals must be adequately trained to identify these disorders in the children they are teaching.

Arriving at a diagnosis of autism typically involves experienced professionals gathering information about the child's behavior from the parents and from direct observation of the child. In the United States, the current criteria for diagnosing autism and other types of pervasive developmental disorders are those given in the *American Psychiatric Association's Diagnostic and Statistical Manual*, Fourth Edition. In New York State, only licensed physicians and licensed clinical psychologists are authorized to make a formal diagnosis of autism.⁴³

Assessing children with autism can be complex. Some manifestations of autism are also seen in children who do not have autism but have other conditions such as cognitive delays, language disorders, attention deficit and hyperactivity disorders, and various types of emotional problems. Part of the diagnostic process is to identify if a child has an ASD or one of these other conditions. Optimal clinical practice and specific practice regulations suggest that assessments be conducted by professionals skilled in assessing autism and experienced in working with children to assess communication, behavior and developmental abilities. Although in New York State licensed

⁴³ New York State Department of Health, Early Intervention Program, Clinical Practice Guideline.

psychologists and physicians are the only individuals qualified to diagnose autism, experienced professionals who work with young children may be trained to recognize autistic-like behaviors and make appropriate referrals.

B. Treatment Debate and Characteristics of Effective Interventions

There are both behavioral and developmental approaches to the treatment of children with ASDs. The developmental models are based upon the assumption that a child's symptoms reflect unique biologically-based processing difficulties that may involve affect, sensory modulation and processing, motor planning and symbol formation. Relationships and affective interactions are impacted secondarily, and intervention is aimed at helping a child try to work around the processing difficulties to reestablish affective contact. The behavioral approaches include any method that changes behavior in systematic and measurable ways. These approaches are characterized by intensive one-on-one interventions aimed at rewarding appropriate behaviors.

Traditional behavioral interventions impose structure in the form of distraction-free environments and presentation of opportunities to respond to discrete trials. Appropriate behavior or a particular response is rewarded when it occurs, thus reinforcing the conduct or specific response. The vast majority of ASD intervention research has been conducted in the behavioral area. Researchers, educators and clinicians have studied the effects of applied behavioral analysis (ABA), a set of principles based on behavior approaches using discrete trial training. Overall, the development and learning outcomes for children with autism who have ABA therapy have been extremely positive. Because ABA has been empirically validated as a methodology for effective

instruction of children with ASDs, it has become widely used by therapists who treat ASD children. Many school districts have begun to provide ABA therapies for students with autism.⁴⁴ The New York State Department of Health, which administers the statewide Early Intervention program for children with developmental delays from birth to three, has endorsed ABA as the treatment of choice for individuals with autism.⁴⁵

Comprehensive behavioral interventions have modified traditional techniques in ways that permit instruction in more natural learning environments. The LEAP model (Learning Experiences, an Alternative Program for Preschoolers and their Parents located at the University of Colorado) is an example of a methodology that was developed as part of the evolution of ABA. It was the first to recognize the importance of direct instruction in peer-related social behaviors, and that more natural instructional settings were required to accommodate the presence of typically developing classmates. The TEACCH model (Treatment and Education of Autistic and Related Communication Handicapped Children at the University of North Carolina, Chapel Hill) has developed a communication curriculum that makes use of behavioral procedures with adjustments that incorporate more naturalistic procedures along with alternative communication strategies for nonverbal children. Incidental teaching incorporates the technical procedures generated by ABA research into the environmental contexts in which social and communication behaviors typically occur for children without disabilities.

There is general agreement across comprehensive intervention programs about a number of features of effective programs. One common element among the successful

⁴⁴ Patricia Grzywacz, Esq. And Lisa Lombardo, *Serving Students with Autism: The Debate over Effective Therapies*, LRP Publications (1999).

⁴⁵ *Developing a Solution to the Current Crisis in the Education of Children with Autism*, A Proposal to the New York State Legislature by the Autism Coalition of the Empire State, June 11, 2000.

models is that they all recognize the importance of early intervention in a child's life, ideally before the child reaches school age. Further, they all call for participation by the child for at least 20 hours per week, and often for far more than that. The most effective programs generally operate on a full-year (rather than a school-year) basis. Even those programs (i.e. TEACCH) which provide fewer hours per week of interventions are generally accompanied by other educational and therapeutic interventions, making these programs equally intensive overall.

Successful programs have found that it is critical that families be actively involved in their children's treatment. Although the manner in which parents are asked to participate differs across programs and approaches, there is consensus that parents must be involved in some capacity, at a minimum participating in team treatment meetings regarding their children. Successful programs employ staff that are highly trained and specialized in autism. Standardized training protocols are available which permit the replication of model programs outside of their original venue. Of course, in order to effectively replicate successful model programs, it is necessary to perform multidimensional program evaluation (to ensure, for instance, that the core interventions are being implemented properly). The curricula must provide for systematic teaching in order to guide the teaching interactions.⁴⁶ Because the curriculum is so highly planned, it is also necessary that the physical environment be appropriate for the proper intervention services. For instance, consistent across programs is the existence of predictable daily routines, which are organized according to written schedules of activities. It is thus necessary to have the physical capacity to accommodate these activities. An ongoing assessment of children's progress is essential to the success of an intervention program.

⁴⁶ Curriculum materials are commercially packaged by successful model programs.

The adult/child ratios are without exception kept low in successful programs in order to ensure that individual children's needs can be met.

Successful programs serving children with ASDs must explicitly address the communication irregularities associated with the disorders. They must address communication skills (whether by improving verbal skills or developing alternative means of communication), engagement (i.e. sustained attention to one activity or person), social interactions, play skills and cognitive and academic skills. Obviously, the emphasis of some skills over others may be appropriate based upon the age, developmental stage, or individualized needs of a particular child. In any event, the use of carefully planned, research-based teaching procedures must include plans for the generalization of the skills taught.

Studies have shown that intensive intervention for children with ASDs makes a clinically significant difference for many children, although methodological limitations preclude definitive attributions of program success to specific intervention procedures. Nevertheless, the consensus across programs is generally strong concerning the desirability of: early entry into an intervention program; active engagement in intensive instructional programming; use of planned teaching opportunities; and sufficient amounts of adult attention in one-to-one or very small group instruction to meet individualized goals.⁴⁷ Overall, effective programs are more similar than different in terms of levels of organization, staffing, ongoing monitoring, and the use of certain techniques, such as discrete trials, incidental learning, and the structured teaching period.

⁴⁷ *Educating Children with Autism*, Committee on Educational Interventions for Children with Autism, Division of Behavioral and Social Sciences and Education National Research Council, National Academy Press, Washington, DC (2001).

IV. New York's Autism Programs

In August 2001, the New York State Education Department (SED) and the State University at Albany published the Autism Program Quality Indicators (APQI), a compilation of the best practices in educating students with autism. They were developed to serve as a means of guiding quality improvement activities for schools and programs serving children with autism in New York State. The APQI was developed by the New York Autism Network at the request of the SED to promote the goal that all students in the state of New York receive special education that meets high educational standards by providing benchmarks of quality programs that result in successful outcomes for students with autism. The APQI are a compilation of research-based components that have been linked to high quality and effective education programs for students with autism. The items on the APQI were derived from a variety of sources including a review of the scientific literature, professional experience and input and review by national experts in the field of autism. They were designed for use by the schools in periodic self-reviews of the programs and services provided to children with autism and to address quality improvement as needed.⁴⁸ In this report we had hoped to review the public school placements using the APQI guidelines. Unfortunately, we were not allowed to visit a single school that serves children with autism, unless we had to do so for a particular client, and thus we could not conduct the type of review we had hoped.

Thus, to assess service delivery in New York City, we had to rely on limited data from SED, anecdotal reports, cases worked on by AFC and interviews with professionals,

⁴⁸ AFC had hoped to conduct a review of autism programs using the APQI. This was not possible as AFC was not able to obtain physical access to the various programs it would have liked to have reviewed. It is worth noting that it appears that the APQI have not been utilized by any entity in evaluating autism programs.

since we were not able to obtain empirical data concerning service delivery. Since most children classified as autistic are being assessed using alternative assessment measures, one cannot examine school performance data, such as test scores and graduation rates, to obtain an accurate picture of service delivery.

To compile this report, AFC sent two Freedom of Information Law (FOIL) requests to the New York City DOE, requesting that we be provided with any directive, memorandum, and guidance document concerning service delivery for children with ASD. To date, the DOE has not provided a single document that describes their programs for children with autism, methodologies offered, or training provided to staff. Thus, it was difficult to collect information.

Data obtained from SED does show the types of environments in which children with autism are served through the special education system. According to SED, 2100 of the City’s children classified as autistic are served in public school placements and 1178 are served outside regular school facilities.

Time Spent Outside of General Education Setting For Autistic Children in New York City

Time outside classroom	Age 4-5	Age 6-11	Age 12-13	Age 14-17	Age 18-21	Total
20% or less	16	182	26	44	14	282
21% -60%	1	0	1	0	0	2
More than 60%	211	1082	199	207	127	1816
						2100

Source: PD-1/4 Reports to New York State Education Department

Type of Setting for Autistic Children in New York City

Type of Setting	Age 4-5	Age 6-11	Age 12-13	Age 14-17	Age 18-21	Total
Public Day School	90	277	67	188	78	700
Private Day	41	270	51	34	16	412
Pub. Residen.	0	0	0	0	0	0
Private Residen.	0	19	12	15	15	61
Home/Hosp.	0	5		0	0	5
						1178

Source: PD-1/4 Reports to New York State Education Department

This data demonstrates that at least two thirds of all children classified as autistic are served in the public schools. The large majority are not served in their regular schools in inclusion programs, but instead are in segregated classes in District 75, which is New York City’s citywide special education district for severely disabled students.

Unfortunately, the New York City public schools do not provide the sort of consistent, research-driven programs contemplated by the APQI. Parents of children with ASDs report having great difficulty in obtaining what they believed to be beneficial treatment methodologies (such as ABA or TEACCH) once their child had entered a school age program. These parents also report that the programs in which their children were enrolled, in fact, did not meet the needs of their children.⁴⁹ Many programs that claim to offer ABA demonstrate little if any expertise in the delivery of the interventions. Many education programs provide an “eclectic” approach and use a variety of teaching

⁴⁹ Saunders, A & Jesinkey, W., *Experiences of Families with Autistic Children in the Service-Delivery System in New York City*.

methodologies. For instance, ABA is used for only a small fraction of the school day (one or two hours), and the staff delivering the services are not trained and supervised in the delivery of these interventions.⁵⁰ Parents report that their ASD children are being placed with physically handicapped and emotionally disturbed children, and that untrained teachers were trying to force their children to speak. Parents also reported that their children came home from school dirty and soiled.⁵¹ These are the obvious consequences of inappropriate placements and a lack of adequately trained staff. These programs violate best practices for educating children with ASDs, may have no benefit to the children enrolled in them and, as will be demonstrated later in this report, may also violate federal law.

AFC staff recently discovered a document on the DOE's website that was apparently developed in 2003, that describes methodologies for children with ASD that are allegedly used by the DOE, including TEACCH, ABA, the Miller Method, PECS, Links to Language and Sensory Integration. This site contains some questionable information for parents that suggests that school administrators can govern the type of methodologies used and the parents are free to switch their children from methodology to methodology, depending on seat availability.⁵² This information needs to be explored further.

As the statistics demonstrate, at least one third of the children who are classified as autistic are served in private schools. Many of these programs employ research-based

⁵⁰ Developing a Solution to the Current Crisis in the Education of Children with Autism, A Proposal to the New York State Legislature by the Autism Coalition of the Empire State, June 11, 2000. Parents of children with ASDs echoed these concerns, and specifically emphasized the lack of support with which classroom teachers are provided.

⁵¹ Saunders & Jesinkey.

⁵² <http://schools.nycenet.edu/d75/ASD/FAQs.html>. 4/30/04

methodologies with great success. For instance, Eden II, a private autism research and treatment center located on Staten Island, is often cited by parents and advocates as a model for successful programming. The program at Eden II uses proactive behavior management strategies consistently in order to prevent recurrence of problem behaviors. Appropriate skills and behaviors are taught and behavior intervention plans focus on long-term outcomes.⁵³ Personnel there are knowledgeable in assessment methods of autistic children and in strategies to enhance speech, language and communication. In addition, Eden II uses research-based techniques to assess and treat problem behaviors.⁵⁴

The NYCLI in Whitestone, New York, where New York City public school students are often placed, is another example of a private program that uses research-based methodologies in a consistent way. It is a replica of a model program first implemented by the Princeton Childhood Developmental Institute (PCDI) in Princeton, New Jersey and, like its model, achieves positive results for its students.⁵⁵

V. AFC's Experience

AFC assists thousands of parents of children with disabilities to obtain appropriate educational services for their children and thus is able to identify trends in the provision of educational services. Most of the families with whom AFC works are black and Hispanic. As race and poverty are highly correlated with one another, most of these families are poor. AFC has worked with many individual students with ASDs in an effort to secure appropriate placements and educational services for them. Consequently, through its institutional experience, AFC has had the opportunity to observe the flaws in the way children with ASDs are both diagnosed and treated by the public education

⁵³ Joanne Gerenser, Ph.D., Eden II.

⁵⁴ Id.

⁵⁵ Joanne Buccellato, AFC.

system. Through an examination of its own cases, AFC has begun to analyze the problem of educational service provision to these children. A review of ten case files of special education students with ASDs, as well as evidence obtained from parents and education professionals in New York City, indicates that, in a variety of ways, the legal requirements outlined above, as well as standards of good practice, are not being met in educating children with ASDs.

A. Case File Review

Stuart K.⁵⁶

Stuart is a seven-year-old who was first evaluated and identified as autistic in 1999 when he was three. His mother and pediatrician referred Stuart to the Committee on Pre-School Education and he was placed in an appropriate pre-school center-based program. As a result of his early diagnosis and his mother's active involvement, Stuart received special education services as a pre-schooler. However, when he transitioned from pre-school to a school age program, the Committee on Special Education labeled him speech-impaired. According to the child's parent, this re-labeling was due to the fact that there was no appropriate placement available for Stuart. By labeling him as speech-impaired, the NYC DOE was able to place Stuart in a classroom with a 12:1:1 ratio where his parent reports that he deteriorated for a year. The classroom teacher told the parent that she was aware that her classroom was an inappropriate placement for Stuart, but, for fear of some sort of retaliation, she refused to say anything to the NYC DOE. Stuart's parent had Stuart privately evaluated for the second time in December 2001. He was again diagnosed as autistic. Stuart's case went back to the CSE in July 2002 and this time they agreed to a classification of autism. They recommended a program with a 6:1:1

⁵⁶ Pseudonyms are employed in order to protect the identity of the children referenced herein.

ratio and offered a placement for September 2002 in a program that had not yet opened. The parent contacted AFC and began to search for a private placement for Stuart. With the help of AFC, the parent found a private placement for Stuart for which she was awarded reimbursement. Stuart began in this placement this school year and has been progressing well.

Nathaniel B.

Nathaniel is a 17-year-old male who was first identified as in need of special education services when he was two due to a referral by his pediatrician. When he became school age, he was properly classified as autistic and placed in a special class, with related services. Nathaniel was profoundly delayed. It was reported by his teachers that he did not interact with his peers. At the age of 11, he was assigned a paraprofessional in order to provide toilet training. By the time he was 12 it was clear that due to the profound nature of Nathaniel's developmental delays and his problematic behaviors, he should be placed in a residential program where he could be provided with consistent, round-the-clock care. Despite this recommendation, he was placed in a special education classroom. Nathaniel was clearly making no progress, but his IEPs continued to recommend the same classroom and the same related services. At age 13, the findings of Nathaniel's NYC DOE evaluation were that he was non-verbal, non-communicative, and was still wearing diapers. Psychological testing was not done due to Nathaniel's profound inability to relate to others. It was reported that he acted out and posed a danger to others. It was again indicated that he should receive a residential program.

Nevertheless, Nathaniel was maintained at the same placement. His IEP did not include a functional behavioral assessment and the school utilized no behavioral treatments. His difficult behaviors (i.e. flinging of feces and urine) were complained about by the teachers and other staff, but no behavior modification program was put in place. His aggressive and anti-social behaviors continued until he was suspended from the bus which took him to and from school, thereby rendering it impossible for him to attend school at all. At this point, Nathaniel's parents contacted AFC. Finally, after obtaining AFC's assistance, in June 2001, when Nathaniel was 14 years old, he was approved for a change in program (at public expense) and has since resided at the Judge Rottenberg Center in Massachusetts. Within three months of entering the program, his mother reported that he was a totally different child, able to communicate his basic needs and displaying none of the anti-social acting out that he had in the past.⁵⁷

Michael H.

Michael is a six-year-old male who was first diagnosed as autistic when he was in pre-school. A private evaluator, obtained by his parent, diagnosed him. Despite this diagnosis, when he turned five and was evaluated by the CSE, he was classified as speech-impaired and placed in an 8:1:1 classroom where he did not do well. The parent then requested that new evaluations be conducted. The NYC DOE had these evaluations performed after which they agreed to change his classification to autistic. Michael was then placed in a new classroom within the same school (in a 6:1:1 class) where some of the research-based methodologies were used (ABA, PECS, and TEACCH). However, the IEP did not indicate how much of these methodologies were to be used and, in fact, it appears that he was given approximately 35 minutes per day of such instruction. The

⁵⁷ Apparently, this was accomplished using aversion (or shock) treatments.

parents reported that even this minimal use of ABA seemed to produce improvements in Michael's behavior. However, at the beginning of this academic year, Michael was placed in a classroom that did not employ ABA techniques. As a consequence Michael's parents brought his case to AFC, where a staff member was assigned. With the help of the advocate, a referral for a private placement was obtained from the NYC DOE and Michael is currently awaiting a private school placement.

Justin I.

Justin is a 13-year-old boy who was originally diagnosed with Pervasive Developmental Disorder, NOS when he was three-and-a-half years old. He was diagnosed through a pediatric neurodevelopmental evaluation performed at his neighborhood clinic. He was provided with pre-school special education services until he was five. At this time he was classified as speech-impaired by the CSE and placed in a kindergarten class with both general and special education students. An educational evaluation performed during his kindergarten year indicated that Justin's behavior suggested autistic tendencies. However, it was also observed that he was able to absorb certain skills at or above his grade level. A psychiatric evaluation, performed by the NYC DOE that same year, indicated that he did not meet the criteria for autism for special education purposes, although PDD was still a possible diagnosis. Justin continued to be classified as speech-impaired until he was seven, at which time his classification was switched to learning disabled. At eight years of age, a psychological evaluation indicated that his diagnosis of PDD-NOS was accurate. At eight years old, Justin's classification was switched back to speech-impaired. His IEP indicated that he should receive related services including speech and language and counseling services.

No research-based methodological techniques for the treatment of children with autism were recommended. Justin's classification was, in total, changed five times. Each time his classification was changed, he was placed in a different type of public special education classroom. Justin made no progress in any of these classes and no public program appropriate to meet Justin's needs could be found. When AFC became involved in Justin's case, the advocate argued that Justin had essentially exhausted the entirety of what the NYC DOE had to offer him. AFC prevailed in 2001 when Justin was eleven years old and was approved for a private school placement where he remains today.

Bobby H.

Bobby is a five-year-old male who was diagnosed with PDD at a very early age when his mother took him to a medical professional for evaluation. He was classified as a pre-school student with a disability.⁵⁸ He attended a private pre-school program. In the spring of 2002, shortly after Bobby turned five, the CSE classified him as autistic. This classification was most likely based on Bobby's mother's representations regarding her child's condition, as no medical or psychological evaluation indicated an actual diagnosis of autism.⁵⁹ Bobby's IEP indicated that he should be placed in a special education classroom and receive related services in speech and language, occupational and physical therapy and counseling. However, no recommendation was made for any of the research-based methodologies used to treat autistic children. Bobby was placed in a classroom with severely autistic children, the majority of whom were far lower functioning than he (they were mostly entirely nonverbal). Dissatisfied with the availability of appropriate public placements for her son, Bobby's mother looked at several different private

⁵⁸ Pre-school students are not classified as having particular disabilities.

⁵⁹ In New York State only a medical doctor or licensed psychologist is qualified to make a diagnosis of autism.

schools, finally settling on one that emphasized the facilitating of social interactions by the teachers. Bobby's mother came to AFC in order to attempt to receive reimbursement for the costs of this placement. With the help of an advocate, Bobby's family was awarded full reimbursement for the cost of this school where Bobby has been a student all of this academic year. According to his mother, Bobby has made enormous progress in this setting, which she feels is structured to meet his individual needs.

Adam J.

Adam is a ten-year-old who, at age five, was dually classified by the NYC DOE as both emotionally disturbed and speech impaired. When he was five years old, unable to handle his behavior, his school actually requested that he stay home unless his mother was available to stay with him throughout the school day. He was re-classified as solely speech-impaired at age six. A few months later his classification was changed to emotionally disturbed. Adam displayed behavior and communication difficulties and had poor interpersonal relationships. In addition, he was moved among classrooms several times during this period. When Adam was almost seven, he was finally classified as autistic although no formal diagnosis was ever made. He was recommended for a special education class with related services including speech and language and counseling. Nevertheless, toward the end of his fourth grade year, when he was nine, Adam's IEP indicated that he should be receiving instruction year-round and that he should be placed in an inclusion classroom (a class including both general and special education students). Adam was placed in such a class at that time. However, unable to cope with the demands placed upon him in a general education classroom, Adam was suspended from that class in May 2002 and sat alone in a room through the fall. It was at this time that Adam's

case came to the attention of AFC. After conducting a hearing on the issue, one of AFC's advocates obtained an order to place Adam back in the classroom. The order was issued in the middle of October 2002 and Adam was, in fact, placed back in the classroom in November 2002. Due to the efforts of AFC and Adam's parent to make the NYC DOE understand his condition, Adam now has his own paraprofessional assigned to shadow him and he remains in this fifth grade inclusion classroom.

Lily R.

Lily is a 16-year-old girl who was first diagnosed as having Asperger's Syndrome (high-functioning autism) at the age of three when her mother had her evaluated. At age four, after she was evaluated by the NYC DOE, her mother was told that she would do well in public school programs. Although she was classified by the NYC DOE as autistic, she was never placed in a public school classroom designed specifically for autistic students. Instead, she was put in a general education class where she remained from kindergarten through the sixth grade. She spent most of these seven school years hiding in closets and under desks. At some point during her sixth grade year, Lily left school altogether and received home instruction. At her request, she returned to school in the eighth grade after which she had a psychological breakdown and spent three weeks in the hospital undergoing psychological treatment. At her CSE meeting in September of 2001, when Lily was 14, her mother was told that Lily's classification was going to be changed from autistic to emotionally disturbed (specifically, school-phobic) as the NYC DOE had no programs available for autistic students like Lily. The CSE recommended a special education classroom. Later that same academic year, Lily was evaluated educationally and found to be functioning at or above grade level in all academic areas

tested and had a composite IQ score of 94, just slightly below average. She was also found to suffer from panic disorder and marijuana abuse, as well as Asperger's Disorder. At this time AFC was contacted by Lily's mother and became involved with Lily's case. AFC and Lily's mother together were able to get Lily placed at a private school for autistic students at public expense. However, already a teenager, Lily's behavioral and social problems are deep-seated. This private placement failed and Lily is back to receiving home instruction by the NYC DOE.

Juan D.

Juan is an 11-year-old who was first diagnosed with Asperger's Syndrome at the age of four by a center for the evaluation of developmental disabilities affiliated with a medical school in the Bronx. Nevertheless, the CSE classified Juan as speech-impaired and placed him in several consecutive inappropriate classrooms. When he was eight, Juan was re-evaluated at the same center where his parents had brought him when he was much younger. At this time, Juan's full-scale IQ score was 115. He was found to have above average cognitive functioning but presented as anxious. He was found to exhibit average abilities with receptive and expressive language. Juan's major problem was noted to be his inability to socialize appropriately. The examiner noted the child's admission that he has no friends. Despite these findings, in the spring of 2000, just a few months after this testing was conducted, he was again classified as speech impaired by the CSE and recommended for a general education program with supplementary services relating to his speech. Despite Juan's total inability to socialize with his peers, at his IEP annual review the following spring (2001), he was classified as speech impaired again and recommended for exactly the same program and services that had been recommended

the previous year. During the 2001-2002 academic year, his socialization problems led to security issues at school and it became unsafe for him to attend school at all. It was at this time that AFC was contacted by Juan's parent. AFC and the parent located a private placement for Juan and obtained the right to receive reimbursement for the costs of tuition obtained. Juan spent the 2002-2003 academic year at Learning Spring Academy where he made tremendous progress and, a month after enrolling, was invited to his first-ever birthday party. Juan has at this time become too old for the Learning Spring Academy but the NYC DOE has recommended that he be placed in another similar special private school for the upcoming academic year.

Dennis B.

Dennis is an 11-year-old who was diagnosed at age six with Asperger's Syndrome after his mother sought his evaluation at a private hospital. He suffers from sensory integration problems related to his Asperger's Syndrome. Despite his diagnosis, the Committee on Special Education (CSE) in his district classified Dennis as emotionally disturbed on his spring 1999 IEP (when he was seven) and placed him in a class with children suffering from severe behavioral disorders. His mother reports that during the period of this placement, Dennis regressed significantly. Recognizing that this sort of chaotic placement was harmful for her son, Dennis' mother sought the right to send Dennis to a private (non-public) school at public expense. In the summer of 2000 (when he was eight), the CSE changed Dennis' classification to autism and referred his case for consideration of a non-public school placement. Due to his mother's efforts, Dennis was placed in an autistic class at a non-public school where he participated in the highly structured TEACCH program and did quite well. However, the class proved to be too

low functioning for him, and consequently, the school moved Dennis to a classroom not designed for autistic students. Dennis performed very poorly in this class because none of the class's teaching staff were trained to deal with his sensory integration and other Asperger's-related issues. This inappropriate placement led to various physical altercations. When Dennis' continued placement in that class became unsafe, his mother removed Dennis from the school altogether. Again, the CSE offered Dennis a public school classroom with emotionally disturbed children similar to the placement that had originally led his mother to remove him from public school. Dennis' mother rejected the CSE's offer, and Dennis began to receive home instruction. He received no related services, however, and the teacher provided by the Department of Education was not even certified to teach special education. At this time Dennis' mother became sufficiently frustrated that she approached AFC for help. AFC obtained appropriate related services for Dennis while he continued home instruction, and ultimately won Dennis the right to attend another private school at Department of Education's expense. Dennis remains in that placement where he receives daily classroom education plus related services of speech, occupational, and physical therapies. He also receives outside counseling through a public service agency.

In order for Dennis to begin school at his current placement, the school decided to create a new class to accommodate Asperger's-diagnosed students (who are generally higher functioning socially than regular autism-spectrum children). Although Dennis is progressing in his current placement, his classmates are still well below him in developing social functioning skills. Therefore, AFC advocates continue to seek a school

environment that addresses both Dennis' low academic skills and his high social functioning abilities.

Bethany W.

Bethany is a six-year-old who began receiving early intervention services before she turned three after her mother had her evaluated privately and development delays were discovered. Bethany was diagnosed as autistic before she turned five and was formally classified as such by the CSE. In fact, she received pre-school services that included ABA. Just before her fifth birthday, the CSE reviewed her case and recommended her for a special education class with related services. Her mother pursued the right to send Bethany to a private school for her kindergarten year and won. When it came time for Bethany to enter the first grade, the CSE again made a recommendation for a public special education classroom. Bethany's mother took her daughter's case to a hearing to obtain the right to tuition reimbursement for the cost of a private school. She lost. After this loss, she contacted AFC for help. AFC appealed the decision (which is pending) and won Bethany the right to remain in a private placement while she awaits the decision of her case on appeal. In the meantime, AFC pursued the case on different grounds from those pursued by Bethany's mother at the first hearing. AFC won and consequently, regardless of the appellate decision, Bethany may remain in her private school placement where she receives five hours per day of ABA and where a discrete trial methodology is used. Bethany is doing quite well in this program where she is in a class with children similar to herself in terms of their level of functioning.

B. Findings

Much of what can be observed from a review of these particular children's files are failures in the provision of educational services to children with ASDs by practitioners and experts in the field. From the review of the selected AFC files, several specific areas emerge where the NYC DOE is failing or where improvement is urgently needed. All of these concerns are echoed by parents and advocates, as well as by the literature on the topic.

1. Early and Proper Evaluations are Not Made by the NYC DOE

Children suffering with autism spectrum disorders are often not identified early and consequently interventions are not made during the time in these children's lives when they have the best chance of being helped.⁶⁰ According to advocates who work in this area, the problem of identifying and diagnosing children suffering from these disorders is partly a consequence of insufficient knowledge and training in the community, which would alert pediatricians and parents to indications that a child should be evaluated for a possible ASD. It is also a consequence of ill-trained staff within the NYC DOE who are responsible for conducting and interpreting the evaluations.

Notably, it appears from both a review of the case files and discussions with parents and advocates that the earliest diagnoses occur for those children who have been referred by a pediatrician for evaluation. Moreover, these referrals are usually made at the request of the parents.⁶¹ It is significant that nine of the ten students in this sample drawn from AFC's case files had been diagnosed privately, at the behest of their parents, in some instances on more than one occasion. The obvious implication of this finding is

⁶⁰ Dorothy Siegel, NYU Institute for Education and Social Policy.

⁶¹ Joanne Buccellato, parent-advocate.

that more doctors need to be aware of these disorders, and particularly those doctors treating the children of parents who are poor and have fewer resources (educational, economic, etc.) when confronted with their children's possible disability.

Based on interviews with experts and providers, there appears to be a consensus that the problem of proper identification is also a result of a dearth of trained individuals on the committees of the NYC DOE that are charged with the responsibility of evaluating and placing children in special education classrooms. Because these individuals are not knowledgeable about ASDs, they are unable to identify the disorders. Instead, they mischaracterize and hence misclassify these children which, in turn, leads to their inappropriate placements. According to one school psychologist, "The New York City Department of Education does not correctly evaluate children. Most of their evaluators are incompetent.... They rarely use specific testing to see if a child is autistic."⁶² The DOE appears further unable to identify an improper or inadequate evaluation. The evaluation measures utilized with these children are often inappropriate. For example, verbal IQ testing is performed on children who are essentially nonverbal.⁶³ This violates the IDEA requirements that tests be provided and administered according to a child's available mode of communication.⁶⁴

These observations are borne out in the AFC cases examined here. Despite evaluations leading to a diagnosis of autism, the CSE misclassified Stuart K. and Michael H. as speech-impaired.⁶⁵ Despite a finding that Justin I. suffered from PDD-NOS, the CSE classified him as speech-impaired as well. His classification (and consequently the

⁶² Peter Piegari, Ph.D., school psychologist at the League School and private practitioner

⁶³ Joanne Buccellato, parent-advocate.

⁶⁴ 34 CFR § 300.532.

⁶⁵ A second private evaluation was necessary before Stuart would be properly classified as autistic.

special class to which he was assigned) was switched a total of five times, first to learning disabled, then back to speech-impaired, etc. until finally he was awarded a private placement. Juan D., diagnosed with Asperger's Syndrome, was misclassified as speech-impaired despite his obvious difficulties with peer relationships. Dennis B., also diagnosed with Asperger's Syndrome, was classified as emotionally disturbed. Adam J. was classified alternately as emotionally disturbed and speech-impaired (and sometimes given a dual classification) for years before he was finally re-classified as autistic by the CSE.

The problem of inadequate evaluations and the consequent misclassification of children with ASDs could be ameliorated through both the hiring of NYC DOE staff properly educated in the identification and treatment of children with ASDs, as well as by providing training in these areas to already existing staff. Outreach efforts to parents and pediatricians in order to better educate these individuals to recognize the early signs of these disorders is also recommended.

2. Insufficient Appropriate Placements are Provided by the Public Schools

One of the starkest findings, illustrated by the cases summarized above, is that the NYC DOE does not provide a sufficient array of placements able to meet the varied needs of students with ASDs. Many of the students whose cases were examined here ultimately had to be placed privately due to the inability of the public school system to provide placements for them that would be able to meet their individual needs (e.g. Stuart K., Nathaniel B., Bobby H., Dennis B.). Justin I. literally exhausted all of the public school placement types available to him (none of which were appropriate) and was awarded a private school placement because there was simply no place else for him to go.

Due to a lack of available appropriate placements, Adam J. ended up sitting alone in an empty room for several months. And Lily R. spent the bulk of seven school years hiding in closets and under desks due to the paucity of public programs for students like her.⁶⁶ Juan D. was also ultimately placed privately because his public placement was so inappropriate that it had become physically dangerous for him to continue in it.

As noted above, children with ASDs are often misclassified and placed in special education classrooms with, for example, emotionally disturbed or speech and language impaired students where their needs are not addressed and their condition deteriorates. If they are higher functioning intellectually, they may be placed in a general education setting where their issues with socialization are not understood or addressed and where consequently the situation becomes untenable, in some instances escalating to the point where continued attendance at school poses a threat to the child's safety (as occurred in Juan's case). According to a recent report by the Autism Coalition of the Empire State, "[t]he number of center-based autism specific education programs providing intensive empirically validated treatment is insufficient to meet the needs of parents and school districts."⁶⁷

Even when children are properly evaluated and diagnosed (most often by individuals outside of the public school system), inappropriate placements may still be made due both to the dearth of appropriate placements as well as to a lack of understanding of the needs of these children. According to advocates, parents and practitioners in the field, the public programs into which children are placed do not use

⁶⁶ Lily's mother was actually told that because the DOE had no programs available for students like her, her classification would be changed from autistic to emotionally disturbed.

⁶⁷ *Developing a Solution to the Current Crisis in the Education of Children with Autism*, A Proposal to the New York State Legislature by the Autism Coalition of the Empire State, June 11, 2000, at p. 2.

the research-based methodologies that have been proven to be effective with this population of children. When these methodologies are used, they are used sporadically (when the effectiveness of these methods is specially linked with their consistent use) and are often utilized by staff that are not properly educated and adequately trained. For example, even when Michael H. was placed in a classroom that was utilizing research-based methodologies, his IEP did not specify which methods were to be used of the duration of them, despite his parents' reports that ABA was producing improvements in his behavior. The public program in which he was enrolled was using the techniques for only about half an hour per day, a severely 'watered down' approach to the technique that is not only ineffectual, but also, most likely, illegal.

“[Educators lack] training in autism and ... have limited knowledge of effective methodologies, programs and strategies that are essential for this population of students.”⁶⁸ This too is a violation of federal law, which requires that the NYC DOE provide an adequate supply of properly trained staff to meet the needs of the special education population it serves.⁶⁹ This lack of appropriate training may lead directly to violations of law and policy in the education of children with these disorders. For instance, while the APQI guidelines require a functional behavioral assessment and positive behavior supports to address challenging behavior, staff dealing with these children lack the clinical expertise to implement such a program.⁷⁰ “In many cases, kids

⁶⁸ *Developing a Solution to the Current Crisis in the Education of Children with Autism*, A Proposal to the New York State Legislature by the Autism Coalition of the Empire State, June 11, 2000 at p. 2.

⁶⁹ 34 CFR §§ 300.380-382.

⁷⁰ No functional behavior assessment was ever performed for Nathaniel B., despite the need for one.

are suspended or thrown out when no one has ever done a functional behavioral assessment.”⁷¹

According to a staff member at the Eden Institute, this paucity of suitable programs is particularly grim for the higher-functioning children, i.e. those with Asperger’s Syndrome. “Nothing exists for them...they are falling apart. They should be in regular education. Instead, they are labeled as conduct disordered.... They should be with typical kids. They are on grade level. They have social and language problems.”⁷² This concern is echoed by Dr. Shirley Cohen, a renowned autism expert, who has said that these higher-functioning children with ASDs “lack an educational home in the [New York City] public school system.”⁷³

Even more devastating to these children’s development, because there are insufficient numbers of appropriate placements available, as was the case for Nathaniel, Justin, Adam, Lily and Juan, children are forced to endure months or even years of wasted time spent in public school classrooms that fail to address their special needs. As it is essential to these children’s development that their disorder be diagnosed and treated as quickly as possible, this wasted time does unnecessary damage to an already vulnerable population of students. It is well documented that only a small number of children gain access to the most effective programs; “[most] others are denied access and spend years in ineffective programs where their educational and behavioral needs go unmet. In some cases, these alternative placements have proven to be even harmful.”⁷⁴

⁷¹ Peter Piegari, Ph.D.

⁷² Joanne Gerenser, Ph.D., Eden Institute.

⁷³ Presentation given on February 15, 2002 at New York University.

⁷⁴ *Developing a Solution to the Current Crisis in the Education of Children with Autism*, A Proposal to the New York State Legislature by the Autism Coalition of the Empire State, June 11, 2000, at p. 2.

This failure to place children in a setting designed to meet his or her educational needs is not only obviously contrary to best educational practices, but also a violation of the federal legal mandates discussed earlier.

3. IEPs and Services are Inadequate

A further consequence of the lack of properly educated and trained NYC DOE staff is that the students' IEPs are, on their face, insufficient to address their unique and diverse needs. The IEPs do not prescribe the use of research-based methodologies proven to be effective in treating this population of children. Nor do they indicate the necessity of providing some of these students with assistive technology in the way of augmentative communication devices, for instance PECS (Picture Exchange Communication System, which has been demonstrated to enable inarticulate autistic children to express themselves to their teachers and other caregivers) or Dynavox computers (i.e. Dynamyte, which enables communication for older nonverbal children).

Notable in the case review undertaken here were these sorts of omissions to the IEPs. No research-based methodologies were specified in the IEPs of Nathaniel, Michael, Justin or Bobby, despite these students' obvious need for them. And despite the fact that it was evident that no progress was being made from year to year, the IEPs often remained unchanged, recommending the same classroom and services that had proved ineffective (e.g. Nathaniel and Juan⁷⁵). By law, an IEP must include a plan for service provision that will meet the disabled child's needs, and an IEP team must consider the communication needs of a disabled child and whether that child requires assistive

⁷⁵ Juan's IEPs never made any mention of his difficulty in socializing and made no recommendations regarding services to deal with this issue.

technology.⁷⁶ Accordingly, the omissions observed in the IEPs of these children violate the law.

Further, despite the need for consistent interventions at both school and home, and the findings that successful treatment programs require the family's active involvement in the child's treatment, none of the IEPs reviewed for this report identified parent counseling or training as a necessary related service. Individuals in the field report "parents are rarely, if ever, involved in developing their child's IEP."⁷⁷ "Schools do not reach out to parents and involve them...the parents are struggling and they do not get any help or support from the school. This is partly because the schools do not know what they are doing."⁷⁸ Parent counseling and training is specifically mentioned in the IDEA as a related service that must be offered where it is warranted. The absence of recommendations for this service represents a departure from sound educational practice as well as a violation of federal law.⁷⁹

VI. Use of the Law to Obtain More Appropriate Services for Individual Students and Effect Systemic Change

There are several different legal methods that can be considered to assist individual students and to effect systemic change. They include:

⁷⁶ 34 CFR §§ 300.346-347.

⁷⁷ Peter Piegari, Ph.D.

⁷⁸ Chris Smith, Ph.D., a clinical psychologist specializing in children with ASDs

⁷⁹ 34 CFR § 300.24.

1. Individual Representation

As stated above, the IDEA provides a very strong framework of entitlements that are designed to ensure that all children with disabilities receive a free appropriate public education. However, unless a parent has the resources to navigate the system and an in-depth understanding of their child's needs and the services and supports that should be provided, it is clearly very difficult to obtain an adequate educational program. The IDEA's framework, the due process mechanism it offers and, ultimately, the ability to pursue relief through the courts can be powerful tools for creating change. The cases discussed above illustrate the effectiveness of individual representation of parents. In general, even individual cases can result in systemic reform, as district staff learn through experience and work to avoid costly litigation by creating better programming. In addition, changes that benefit one child can have multiplier effects—for example, an order requiring training for a teacher or a paraprofessional will benefit the other children served by that provider. However, it would require a significant volume of cases to draw their attention.

Plainly, providing regular education with supports or traditional special education without considering the unique and complex learning needs of a child with autism is a violation of this law. Thus, each child is entitled to an individualized program, tailored toward meeting his/her IEP goals and participating in the general curriculum. Most of the individual hearings and litigation involving children with autism focus on the issue of methodology and use of research-tested teaching methods. Many hearing officers and courts have ruled in favor of parents who seek to use ABA or another methodology,

provided that the parent can prove that the school district had not previously provided an adequate educational program.

While the law provides that the state education agency or local school district may choose the methodology employed in servicing a special education student, that method must allow the child to benefit from his or her instruction. So, while it is not the student's parents' decision what therapy their child should receive, hearing officers and courts have found that 'watered down' versions of research-based therapies are insufficient to satisfy legal requirements.⁸⁰ Accordingly, those New York City programs that offer an hour or two of ABA to their autistic students may be in violation of federal special education law.⁸¹

2. A Model for Impact Litigation

In the context of provision of early intervention services to autistic children, it was a lawsuit that paved the way to parents' ability to receive research-based treatment for their children. In the early 1990's, none of New York City's center-based early intervention programs offered ABA therapy. Consequently, parents who were interested in providing these services to their children had to hire private providers to come to their homes. This trend came to the attention of a nonprofit group, New York Lawyers for the Public Interest (NYLPI). NYLPI saw the opportunity for policy change through lawsuits brought by these parents against the NYC DOE (then the NYC Board of Education) for reimbursement of these expenses. In order to accomplish this, several large law firms were recruited to handle, on a *pro bono* basis, the special education hearings at which the

⁸⁰ Delaware County Intermediate Unit v. Martin and Melinda K., 20 IDELR 363.

⁸¹ A review of relevant case law demonstrates that while courts more often than not side with the districts, there is substantial ability on the part of parents to obtain alternative services for their child and be reimbursed for these, even when such services are provided by unlicensed personnel.

parents would seek an award of compensation for these out-of-pocket expenses. The hope was that victories in multiple suits for reimbursement would force a change in policy regarding the provision of ABA therapy and/or payment for it.

Ultimately, one of the cases went all the way up to the Second Circuit where the Court ruled that due to the IDEA's clear requirement that states must provide early intervention services through qualified personnel, the parent was entitled to reimbursement for expenses incurred in privately obtaining ABA therapy.⁸² The result of the group of cases brought by NYLPI and the firms with which it worked was that a precedent was set entitling parents to the costs associated with providing ABA therapy to children in need of this service. Further, the New York State Department of Health began to develop guidelines for the provision of ABA therapy as an early intervention service to autistic children. Notably, the parents represented in this group of cases were mostly white and middle-class. They paved the way for others to receive these services.

The current challenge is to reach communities of color to enable their children to take similar advantage of effective treatment methodologies.

3. Other Legal Strategies

In addition to individualized representation through hearings and litigation, there are two other legal tools by which change may be achieved. As mentioned above, the IDEA contains a state-complaint procedure, whereby parents or organizations can file complaints with SED concerning failures on the part of the school districts to follow the IDEA or state law. Since the SED has an independent obligation to ensure that children

⁸² Still v. DeBuono 101 F.3d 888 (2d Cir. 1996).

are receiving FAPE throughout the state, a targeted campaign of filing state complaints could perhaps engage SED in a more active effort to improve service delivery in NYC. However, this process can be slow and parents may not be able to wait for these complaints to be resolved. The second non-litigation strategy could involve complaints under Section 504 of the Rehabilitation Act of 1973 filed with the U.S. DOE. However, these complaints can take a long time to resolve. These two strategies could, perhaps, be combined with other direct services efforts to try to obtain changes to the system without resorting to litigation

VII. Conclusion

As set forth above throughout this paper, our analysis revealed a number of systemic failures.

- Children are mis-diagnosed or not identified until they are school-age and many assessment professionals in NYC public schools do not have the skills or resources to recognize and address the needs of children with ASD.
- The procedural requirements of the IDEA are being flouted, resulting in IEPs and program recommendations that are wholly inadequate and violative of law.
- The quality of the services and programs offered by the public schools to children with ASDs need improvement and do not incorporate the use of research-based methodologies in order to provide adequate treatment to children with ASDs.
- Educators and staff working with children with ASD lack training and skills to work with children who have ASD.
- Poor parents of color have virtually no information about the special education system or ASD, which hampers their ability to ensure that their children are identified early enough and provided better quality services through the special education system.

- Poor parents of color do not have sufficient access to legal assistance or medical professionals who can identify the signs of children with ASD and make appropriate referrals.

Clearly, this report indicates the need to reassess the services available for students with ASD, from the early stages of evaluation and identification to placement. It is evident from the frequency of misdiagnosis revealed in AFC cases that there needs to be better staff training and public knowledge about ASD so as to lead to earlier identification and more effective treatment. In particular, poor parents of color need to be better informed about ASD so that they can ensure appropriate and quality services for their children. These parents must be educated on the disorders and their treatments, as well as on the organization of the education system and the provision of special education services. Furthermore, this report reveals the need for an overall improvement and in the quality of services available to students with ASD, which can be achieved by starting with some of the action steps outlined above.

Appendix A

**Table AA9 Number of Children Served Under IDEA by Disability and Age Group,
During School Years 1992-1993 Through 2001-2002**

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Table AA9					
Number of Children Served Under IDEA by Disability and Age Group,					
During School Years 1992-93 Through 2001-02					
AGE GROUPS 0-2, 3-5, 3-21					
	1992-93	1993-94	1994-95	1995-96	1996-97
AGE GROUP 0-2	74,830	152,287	165,351	177,286	186,527
AGE GROUP 3-5	455,449	491,685	522,709	548,593	557,070
AGE GROUP 3-21	5,081,023	5,271,044	5,430,220	5,627,544	5,787,842

Data from 1992-93 through 1993-94 for all age groups include children with disabilities served under Chapter 1 of ESEA (SOP). Beginning in 1994-95, all services to children and youth with disabilities were provided only through IDEA, Parts B and C.

States had the option of reporting children ages 3-9 under developmental delay beginning in 1997-98.

Data based on the December 1, 2001 count, updated as of August 30, 2002.

U.S. Department of Education, Office of Special Education Programs, Data Analysis System (DANS)

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Table AA9

Number of Children Served Under IDEA by Disability and Age Group,

During School Years 1992-93 Through 2001-02

AGE GROUPS 0-2, 3-5, 3-21

	1997-98	1998-99	1999-2000	2000-01	2001-02
AGE GROUP 0-2	196,337	189,462	206,111	232,815	247,433
AGE GROUP 3-5	570,315	573,645	589,133	600,593	620,195
AGE GROUP 3-21	5,967,298	6,113,440	6,267,129	6,374,934	6,487,429

Data from 1992-93 through 1993-94 for all age groups include children with disabilities served under Chapter 1 of ESEA (SOP). Beginning in 1994-95, all services to children and youth with disabilities were provided only through IDEA, Parts B and C.

States had the option of reporting children ages 3-9 under developmental delay beginning in 1997-98.

Data based on the December 1, 2001 count, updated as of August 30, 2002.

U.S. Department of Education, Office of Special Education Programs, Data Analysis System (DANS).

Table AA9**Number of Children Served Under IDEA by Disability and Age Groups****During School Years 1992-93 Through 2001-2002****AGE GROUP 6-11**

DISABILITY	1992-93	1993-94	1994-95	1995-96	1996-97
SPECIFIC LEARNING DISABILITIES	997,580	1,009,541	1,041,816	1,073,215	1,093,857
SPEECH OR LANGUAGE IMPAIRMENTS	888,935	900,962	905,223	910,788	928,942
MENTAL RETARDATION	209,487	220,301	229,453	235,490	239,286
EMOTIONAL DISTURBANCE	137,269	140,603	144,595	147,368	150,401
MULTIPLE DISABILITIES	52,472	55,073	43,889	46,150	48,489
HEARING IMPAIRMENTS	29,363	31,178	31,464	32,501	32,923
ORTHOPEDIC IMPAIRMENTS	29,138	31,644	33,521	34,530	35,574
OTHER HEALTH IMPAIRMENTS	33,487	43,493	56,856	71,649	84,868
VISUAL IMPAIRMENTS	11,210	11,723	11,557	11,870	11,843
AUTISM	8,914	11,158	13,716	17,666	21,669
DEAF-BLINDNESS	554	564	524	547	489
TRAUMATIC BRAIN INJURY	1,507	2,111	2,871	3,929	4,106
DEVELOPMENTAL DELAY
ALL DISABILITIES	2,399,916	2,458,351	2,515,485	2,585,703	2,652,447

Table AA9

Number of Children Served Under IDEA by Disability and Age Groups

During School Years 1992-93 Through 2001-2002

AGE GROUP 6-11

DISABILITY	1992-93	1993-94	1994-95	1995-96	1996-97
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Data from 1992-93 through 1993-94 for all age groups include children with disabilities served under Chapter 1 of ESEA (SOP). Beginning in 1994-95, all services to children and youth with disabilities were provided only through IDEA, Parts B and C.

States had the option of reporting children ages 3-9 under developmental delay beginning in 1997-98.

Data based on the December 1, 2001 count, updated as of August 30, 2002.

U.S. Department of Education, Office of Special Education Programs, Data Analysis System (DANS).

Table AA9**Number of Children Served Under IDEA by Disability and Age Group****During School Years 1992-1993 Through 2001-2002****AGE GROUP 6-11**

DISABILITY	1997-98	1998-99	1999-2000	2000-01	2001-02
SPECIFIC LEARNING DISABILITIES	1,114,458	1,119,468	1,114,602	1,087,127	1,047,344
SPEECH OR LANGUAGE IMPAIRMENTS	939,430	946,804	956,487	958,583	955,637
MENTAL RETARDATION	240,706	240,226	238,707	232,797	221,062
EMOTIONAL DISTURBANCE	154,034	157,622	160,046	160,636	156,798
MULTIPLE DISABILITIES	51,039	49,636	51,289	54,755	55,824
HEARING IMPAIRMENTS	33,288	33,715	33,728	33,318	33,037
ORTHOPEDIC IMPAIRMENTS	35,668	36,012	36,849	37,216	36,941
OTHER HEALTH IMPAIRMENTS	97,861	110,862	125,090	140,655	156,070
VISUAL IMPAIRMENTS	12,088	12,095	12,492	12,157	12,083
AUTISM	27,342	35,143	43,517	52,461	63,676
DEAF-BLINDNESS	511	650	821	575	663
TRAUMATIC BRAIN INJURY	4,528	4,878	5,222	5,468	7,730
DEVELOPMENTAL DELAY	3,792	11,907	19,263	28,616	45,128
ALL DISABILITIES	2,715,648	2,759,018	2,798,113	2,804,364	2,791,993

Data from 1992-93 through 1993-94 for all age groups include children with disabilities served

Table AA9

Number of Children Served Under IDEA by Disability and Age Group

During School Years 1992-1993 Through 2001-2002

AGE GROUP 6-11

DISABILITY	1997-98	1998-99	1999-2000	2000-01	2001-02
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under Chapter 1 of ESEA (SOP). Beginning in 1994-95, all services to children and youth with disabilities were provided only through IDEA, Parts B and C.

States had the option of reporting children ages 3-9 under developmental delay beginning in 1997-98.

Data based on the December 1, 2001 count, updated as of August 30, 2002.

U.S. Department of Education, Office of Special Education Programs, Data Analysis System (DANS).

Table AA9**Number of Children Served Under IDEA by Disability and Age Group,****During School Years 1992-93 Through 2001-02****AGE GROUP 12-17**

DISABILITY	1992-93	1993-94	1994-95	1995-96	1996-97
SPECIFIC LEARNING DISABILITIES	1,252,188	1,296,829	1,347,294	1,398,602	1,447,496
SPEECH OR LANGUAGE IMPAIRMENTS	104,904	112,581	110,859	111,833	115,352
MENTAL RETARDATION	258,619	269,321	279,214	286,953	291,672
EMOTIONAL DISTURBANCE	242,319	251,524	260,891	267,786	271,230
MULTIPLE DISABILITIES	38,368	42,083	34,231	36,365	38,776
HEARING IMPAIRMENTS	26,966	29,037	29,545	30,983	31,259
ORTHOPEDIC IMPAIRMENTS	19,594	21,321	23,069	24,591	26,528
OTHER HEALTH IMPAIRMENTS	29,150	35,886	46,054	57,714	71,133
VISUAL IMPAIRMENTS	10,641	11,357	11,445	11,864	12,072
AUTISM	4,893	5,832	6,760	8,796	10,078
DEAF-BLINDNESS	599	585	600	619	535
TRAUMATIC BRAIN INJURY	1,844	2,559	3,486	4,558	5,182
ALL DISABILITIES	1,990,085	2,078,915	2,153,448	2,240,664	2,321,313

Data from 1992-93 through 1993-94 for all age groups include children with disabilities served under Chapter 1 of ESEA (SOP). Beginning in 1994-95, all services to children and youth with disabilities were provided only through IDEA, Parts B and C.

States had the option of reporting children ages 3-9 under developmental delay beginning in 1997-98.

Table AA9

Number of Children Served Under IDEA by Disability and Age Group,

During School Years 1992-93 Through 2001-02

AGE GROUP 12-17

DISABILITY	1992-93	1993-94	1994-95	1995-96	1996-97
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Data based on the December 1, 2001 count, updated as of August 30, 2002.

U.S. Department of Education, Office of Special Education Programs, Data Analysis System (DANS).

Table AA9**Number of Children Served Under IDEA by Disability and Age Group,****During School Years 1992-93 Through 2001-02****AGE GROUP 12-17**

DISABILITY	1997-98	1998-99	1999-2000	2000-01	2001-02
SPECIFIC LEARNING DISABILITIES	1,500,946	1,551,701	1,608,672	1,656,074	1,701,847
SPEECH OR LANGUAGE IMPAIRMENTS	119,503	122,565	126,238	129,977	132,910
MENTAL RETARDATION	297,657	303,274	308,617	313,058	316,091
EMOTIONAL DISTURBANCE	275,106	278,930	283,464	288,263	295,429
MULTIPLE DISABILITIES	41,902	44,123	47,035	52,496	56,529
HEARING IMPAIRMENTS	31,785	32,218	32,770	32,834	33,482
ORTHOPEDIC IMPAIRMENTS	27,482	28,867	29,899	30,968	31,912
OTHER HEALTH IMPAIRMENTS	86,677	103,009	121,519	143,845	171,758
VISUAL IMPAIRMENTS	12,033	12,004	11,942	11,901	11,779
AUTISM	12,211	15,480	18,506	22,502	28,593
DEAF-BLINDNESS	597	722	622	523	693
TRAUMATIC BRAIN INJURY	6,045	6,603	7,125	7,714	10,947
ALL DISABILITIES	2,411,944	2,499,496	2,596,409	2,690,155	2,791,970

Table AA9

Number of Children Served Under IDEA by Disability and Age Group,

During School Years 1992-93 Through 2001-02

AGE GROUP 12-17

DISABILITY	1997-98	1998-99	1999-2000	2000-01	2001-02
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Data from 1992-93 through 1993-94 for all age groups include children with disabilities served under Chapter 1 of ESEA (SOP). Beginning in 1994-95, all services to children and youth with disabilities were provided only through IDEA, Parts B and C.

States had the option of reporting children ages 3-9 under developmental delay beginning in 1997-98.

Data based on the December 1, 2001 count, updated as of August 30, 2002.

U.S. Department of Education, Office of Special Education Programs, Data Analysis System (DANS).

Table AA9**Number of Children Served Under IDEA by Disability and Age Group,****During School Years 1992-93 Through 2001-02****AGE GROUP 14-21**

DISABILITY	1992-93	1993-94	1994-95	1995-96	1996-97
SPECIFIC LEARNING DISABILITIES	869,357	908,955	946,020	987,476	1,026,313
SPEECH OR LANGUAGE IMPAIRMENTS	45,266	48,990	48,501	48,904	51,162
MENTAL RETARDATION	231,953	239,356	243,551	250,299	253,884
EMOTIONAL DISTURBANCE	180,850	188,859	196,353	203,947	208,242
MULTIPLE DISABILITIES	36,010	38,697	33,389	35,382	37,316
HEARING IMPAIRMENTS	21,209	22,710	22,956	24,377	24,847
ORTHOPEDIC IMPAIRMENTS	15,948	17,136	18,080	19,009	20,585
OTHER HEALTH IMPAIRMENTS	22,194	26,380	33,094	40,411	48,995
VISUAL IMPAIRMENTS	8,466	9,039	9,095	9,393	9,726
AUTISM	4,784	5,637	6,216	7,746	8,499
DEAF-BLINDNESS	572	570	594	632	539
TRAUMATIC BRAIN INJURY	1,883	2,455	3,263	4,069	4,723
DEVELOPMENTAL DELAY
ALL DISABILITIES	1,438,492	1,508,784	1,561,112	1,631,645	1,694,831

Data from 1992-93 through 1993-94 for all age groups include children with disabilities served under Chapter 1 of ESEA (SOP). Beginning in 1994-95, all services to children and youth with disabilities were provided only through IDEA, Parts B and C.

Table AA9

Number of Children Served Under IDEA by Disability and Age Group,

During School Years 1992-93 Through 2001-02

AGE GROUP 14-21

DISABILITY	1992-93	1993-94	1994-95	1995-96	1996-97
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States had the option of reporting children ages 3-9 under developmental delay beginning in 1997-98.

Data based on the December 1, 2001 count, updated as of August 30, 2002.

U.S. Department of Education, Office of Special Education Programs, Data Analysis System (DANS).

Table AA9**Number of Children Served Under IDEA by Disability and Age Group,****During School Years 1992-93 Through 2001-02****AGE GROUP 14-21**

DISABILITY	1997-98	1998-99	1999-2000	2000-01	2001-02
SPECIFIC LEARNING DISABILITIES	1,064,705	1,100,754	1,139,623	1,165,174	1,199,338
SPEECH OR LANGUAGE IMPAIRMENTS	53,350	55,078	57,725	58,859	59,004
MENTAL RETARDATION	258,981	264,479	268,478	272,063	274,776
EMOTIONAL DISTURBANCE	210,225	212,429	215,840	217,437	222,219
MULTIPLE DISABILITIES	40,417	42,518	45,196	49,315	52,408
HEARING IMPAIRMENTS	25,250	25,486	25,830	25,669	26,105
ORTHOPEDIC IMPAIRMENTS	21,173	22,517	23,440	24,263	24,929
OTHER HEALTH IMPAIRMENTS	58,902	69,693	81,825	96,126	115,054
VISUAL IMPAIRMENTS	9,831	9,917	9,773	9,754	9,757
AUTISM	10,044	12,385	14,731	17,692	21,859
DEAF-BLINDNESS	618	731	649	568	706
TRAUMATIC BRAIN INJURY	5,421	5,934	6,346	6,868	9,312
DEVELOPMENTAL DELAY
ALL DISABILITIES	1,758,917	1,821,921	1,889,456	1,943,788	2,015,467

Data from 1992-93 through 1993-94 for all age groups include children with disabilities served under Chapter 1 of ESEA (SOP). Beginning in 1994-95, all services to children and youth with

Table AA9

Number of Children Served Under IDEA by Disability and Age Group,

During School Years 1992-93 Through 2001-02

AGE GROUP 14-21

DISABILITY	1997-98	1998-99	1999-2000	2000-01	2001-02
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disabilities were provided only through IDEA, Parts B and C.

States had the option of reporting children ages 3-9 under developmental delay beginning in 1997-98.

Data based on the December 1, 2001 count, updated as of August 30, 2002.

U.S. Department of Education, Office of Special Education Programs, Data Analysis System (DANS).

Table AA9**Number of Children Served Under IDEA by Disability and Age Group,****During School Years 1992-93 Through 2001-02****AGE GROUP 18-21**

DISABILITY	1992-93	1993-94	1994-95	1995-96	1996-97
SPECIFIC LEARNING DISABILITIES	116,719	121,295	121,114	130,087	133,054
SPEECH OR LANGUAGE IMPAIRMENTS	4,210	4,442	4,248	4,263	4,447
MENTAL RETARDATION	64,256	64,197	61,850	63,132	62,644
EMOTIONAL DISTURBANCE	22,064	22,824	22,563	24,011	24,648
MULTIPLE DISABILITIES	12,439	12,561	11,500	12,020	12,175
HEARING IMPAIRMENTS	4,287	4,450	4,195	4,555	4,591
ORTHOPEDIC IMPAIRMENTS	3,856	3,887	3,877	4,035	4,240
OTHER HEALTH IMPAIRMENTS	3,426	3,700	4,223	4,798	5,361
VISUAL IMPAIRMENTS	1,693	1,724	1,711	1,756	1,847
AUTISM	1,773	2,068	2,188	2,614	2,628
DEAF-BLINDNESS	241	220	207	221	192
TRAUMATIC BRAIN INJURY	609	725	902	1,092	1,185
ALL DISABILITIES	235,573	242,093	238,578	252,584	257,012

Data from 1992-93 through 1993-94 for all age groups include children with disabilities served

Table AA9

Number of Children Served Under IDEA by Disability and Age Group,

During School Years 1992-93 Through 2001-02

AGE GROUP 18-21

DISABILITY	1992-93	1993-94	1994-95	1995-96	1996-97
<p>under Chapter 1 of ESEA (SOP). Beginning in 1994-95, all services to children and youth with disabilities were provided only through IDEA, Parts B and C.</p> <p>States had the option of reporting children ages 3-9 under developmental delay beginning in 1997-98.</p> <p>Data based on the December 1, 2001 count, updated as of August 30, 2002.</p> <p>U.S. Department of Education, Office of Special Education Programs, Data Analysis System (DANS)</p> <p>.</p>					

Table AA9**Number of Children Served Under IDEA by Disability and Age Group,****During School Years 1992-93 Through 2001-02****AGE GROUP 18-21**

DISABILITY	1997-98	1998-99	1999-2000	2000-01	2001-02
SPECIFIC LEARNING DISABILITIES	139,080	144,441	144,490	138,672	138,045
SPEECH OR LANGUAGE IMPAIRMENTS	4,628	4,779	5,083	4,908	5,047
MENTAL RETARDATION	64,968	67,177	66,957	67,634	68,115
EMOTIONAL DISTURBANCE	25,301	26,212	26,245	25,470	25,400
MULTIPLE DISABILITIES	13,412	14,052	14,675	15,700	16,207
HEARING IMPAIRMENTS	4,707	4,943	4,902	4,665	4,704
ORTHOPEDIC IMPAIRMENTS	4,267	4,557	4,669	4,804	4,970
OTHER HEALTH IMPAIRMENTS	6,603	7,947	8,738	9,475	10,839
VISUAL IMPAIRMENTS	1,910	1,997	1,951	1,950	1,984
AUTISM	2,964	3,441	4,020	4,633	5,635
DEAF-BLINDNESS	212	240	229	220	259
TRAUMATIC BRAIN INJURY	1,341	1,495	1,515	1,691	2,066
ALL DISABILITIES	269,391	281,281	283,474	279,822	283,271

Data from 1992-93 through 1993-94 for all age groups include children with disabilities served under Chapter 1 of ESEA (SOP). Beginning in 1994-95, all services to children and youth with disabilities were provided only through IDEA, Parts B and C.

States had the option of reporting children ages 3-9 under developmental delay beginning in 1997-98.

Data based on the December 1, 2001 count, updated as of August 30, 2002.

Table AA9

Number of Children Served Under IDEA by Disability and Age Group,

During School Years 1992-93 Through 2001-02

AGE GROUP 18-21

DISABILITY	1997-98	1998-99	1999-2000	2000-01	2001-02
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U.S. Department of Education, Office of Special Education Programs, Data Analysis System (DANS).

Table AA9**Number of Children Served Under IDEA by Disability and Age Group,****During School Years 1992-93 Through 2001-02****AGE GROUP 6-21**

DISABILITY	1992-93	1993-94	1994-95	1995-96	1996-97
SPECIFIC LEARNING DISABILITIES	2,366,487	2,427,665	2,510,224	2,601,904	2,674,407
SPEECH OR LANGUAGE IMPAIRMENTS	998,049	1,017,985	1,020,330	1,026,884	1,048,741
MENTAL RETARDATION	532,362	553,819	570,517	585,575	593,602
EMOTIONAL DISTURBANCE	401,652	414,951	428,049	439,165	446,279
MULTIPLE DISABILITIES	103,279	109,717	89,620	94,535	99,440
HEARING IMPAIRMENTS	60,616	64,665	65,204	68,039	68,773
ORTHOPEDIC IMPAIRMENTS	52,588	56,852	60,467	63,156	66,342
OTHER HEALTH IMPAIRMENTS	66,063	83,079	107,133	134,161	161,362
VISUAL IMPAIRMENTS	23,544	24,804	24,713	25,490	25,762
AUTISM	15,580	19,058	22,664	29,076	34,375
DEAF-BLINDNESS	1,394	1,369	1,331	1,387	1,216
TRAUMATIC BRAIN INJURY	3,960	5,395	7,259	9,579	10,473
DEVELOPMENTAL DELAY
ALL DISABILITIES	4,625,574	4,779,359	4,907,511	5,078,951	5,230,772

Data from 1992-93 through 1993-94 for all age groups include children with disabilities served

Table AA9

Number of Children Served Under IDEA by Disability and Age Group,

During School Years 1992-93 Through 2001-02

AGE GROUP 6-21

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DISABILITY	1992-93	1993-94	1994-95	1995-96	1996-97
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under Chapter 1 of ESEA (SOP). Beginning in 1994-95, all services to children and youth with disabilities were provided only through IDEA, Parts B and C.

States had the option of reporting children ages 3-9 under developmental delay beginning in 1997-98.

Data based on the December 1, 2001 count, updated as of August 30, 2002.

U.S. Department of Education, Office of Special Education Programs, Data Analysis System (DANS).

Table AA9**Number of Children Served Under IDEA by Disability and Age Group,****During School Years 1992-93 Through 2001-02****AGE GROUP 6-21**

DISABILITY	1997-98	1998-99	1999-2000	2000-01	2001-02
SPECIFIC LEARNING DISABILITIES	2,754,484	2,815,610	2,867,764	2,881,873	2,887,236
SPEECH OR LANGUAGE IMPAIRMENTS	1,063,561	1,074,148	1,087,808	1,093,468	1,093,594
MENTAL RETARDATION	603,331	610,677	614,281	613,489	605,268
EMOTIONAL DISTURBANCE	454,441	462,764	469,755	474,369	477,627
MULTIPLE DISABILITIES	107,253	107,811	112,999	122,951	128,560
HEARING IMPAIRMENTS	69,783	70,876	71,400	70,817	71,223
ORTHOPEDIC IMPAIRMENTS	67,417	69,436	71,417	72,988	73,823
OTHER HEALTH IMPAIRMENTS	191,141	221,818	255,347	293,975	338,667
VISUAL IMPAIRMENTS	26,031	26,096	26,385	26,008	25,846
AUTISM	42,517	54,064	66,043	79,596	97,904
DEAF-BLINDNESS	1,320	1,612	1,672	1,318	1,615
TRAUMATIC BRAIN INJURY	11,914	12,976	13,862	14,873	20,743
DEVELOPMENTAL DELAY	3,792	11,907	19,263	28,616	45,128
ALL DISABILITIES	5,396,985	5,539,795	5,677,996	5,774,341	5,867,234

Table AA9					
Number of Children Served Under IDEA by Disability and Age Group,					
During School Years 1992-93 Through 2001-02					
AGE GROUP 6-21					
DISABILITY	1997-98	1998-99	1999-2000	2000-01	2001-02
<p>Data from 1992-93 through 1993-94 for all age groups include children with disabilities served under Chapter 1 of ESEA (SOP). Beginning in 1994-95, all services to children and youth with disabilities were provided only through IDEA, Parts B and C.</p> <p>States had the option of reporting children ages 3-9 under developmental delay beginning in 1997-98.</p> <p>Data based on the December 1, 2001 count, updated as of August 30, 2002.</p> <p>U.S. Department of Education, Office of Special Education Programs, Data Analysis System (DANS).</p>					

Source: Data Tables for OSEP State Reported Data, IDEAdata.org