

In The  
**Supreme Court of the United States**

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D.P. ON BEHALF OF E.P., D.P., AND K.P.;  
AND L.P. ON BEHALF OF E.P., D.P., AND K.P.,

*Petitioners,*

v.

SCHOOL BOARD OF BROWARD COUNTY, FLORIDA,

*Respondent.*

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**On Petition For A Writ Of Certiorari  
To The United States Court Of Appeals  
For The Eleventh Circuit**

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**BRIEF OF *AMICUS CURIAE* AUTISM SPEAKS  
IN SUPPORT OF PETITIONERS**

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GARY S. MAYERSON  
Director, Autism Speaks  
Federal Legal  
Appeals Project

MAYERSON & ASSOCIATES  
330 West 38th Street  
Suite 600  
New York, New York 10018  
(212) 265-7200

*Co-counsel for Amicus Curiae  
Autism Speaks*

ROBERT H. PEES  
*Counsel of Record*

MICHAEL D. LOCKARD  
EVANDRO C. GIGANTE

AKIN GUMP STRAUSS HAUER  
& FELD LLP  
590 Madison Avenue  
New York, New York 10022  
(212) 872-1000

*Counsel for Amicus Curiae  
Autism Speaks*

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**INTEREST OF *AMICUS CURIAE***<sup>1</sup>

*Amicus curiae* Autism Speaks is a not-for-profit organization dedicated to increasing awareness of autism spectrum disorders; funding research into the causes, prevention, treatments and potential cures for autism; and advocating for the needs of affected families. Following mergers with other national autism organizations, Autism Speaks is now the largest not-for-profit organization in the world by resources dedicated to autism research, education and treatment and has chapters across the United States, Canada, and the United Kingdom. Autism Speaks works closely with federal, state and local governments, as well as the U.S. military, to meet the needs of the ever-growing population of children with autism and parents of children with autism for access to treatment and education.

Autism Speaks can offer valuable insights into the special educational challenges faced by children with autism and their families, as well as the potential impact of the decision below on thousands of families across the nation. Early, intensive and sustained special education services are critical to giving

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<sup>1</sup> Pursuant to this Court's Rule 37.6 we note that no part of this brief was authored by counsel for any party, and no person or entity other than Autism Speaks, its members, or its counsel made a monetary contribution to the preparation or submission of the brief. This brief was filed with the written consent of all parties. Petitioners received ten days notice pursuant to Rule 37.2, and Respondent has waived their notice provision.

a young child the chance to remediate and overcome the symptoms of autism and to grow into a productive, self-sufficient member of society. While Autism Speaks focuses primarily on children diagnosed with autism, the critical importance of early, appropriate and sustained intervention is common to many developmental disabilities. That is precisely why Congress provided for early intervention programs under Part C of the Individuals with Disabilities Education Act, and why Congress sought to protect the rights of parents and their children with disabilities to the continuation of appropriate services during the pendency of any disputes over a child with disability's educational programming. *See* 20 U.S.C. § 1415(j).



### **PRELIMINARY STATEMENT**

Autism is a serious developmental disability, one that can be emotionally, psychologically and financially devastating to the families of the hundreds of thousands of school-aged children presently diagnosed, and thousands more that are diagnosed each year. But there is strong consensus that nearly all children with autism will benefit from early, appropriate and sustained services, and a significant number will even be able to join regular education classrooms and grow into adults able to enjoy independent and productive lives. The window of opportunity, however, is widest when the child is young, and the damage to the child's potential for development if this opportunity is allowed to lapse can never

be undone. Mistakes at this critical juncture are costly and often irremediable – parents and educators simply cannot afford to learn geology the morning after the earthquake.<sup>2</sup>

The need for early and continuous intervention during the window of opportunity is particularly important to the parents of children with autism spectrum disorders, a population that has grown exponentially in recent years. Until relatively recently, autism was a rarely-diagnosed and little-known condition, but is now more prevalent among children than Down syndrome, diabetes, cystic fibrosis, and cancer. With about 1 in 150 children in the United States suffering from autism spectrum disorder, this is the fastest-growing segment of the IDEA-covered population. As thousands of children are newly diagnosed every year, more parents become familiar with the burdens – emotional and financial – that accompany a diagnosis of autism spectrum disorder.

The decision below exposes children with autism to the risk of seismic catastrophe at a time they can afford it least. Under the Eleventh Circuit’s decision, three-year-old children with autism transitioning from the Individuals with Disabilities Education Act’s

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<sup>2</sup> “We learn geology the morning after the earthquake, on ghastly diagrams of cloven mountains, up-heaved plains, and the dry bed of the sea.” Ralph Waldo Emerson, *Considerations by the Way*, in *THE CONDUCT OF LIFE* 1088 (1860).

(“IDEA” or the “Act”) early intervention program under Part C to the services available to school-aged children under Part B of the Act can be denied appropriate services or even any services at all, and parents would have little or no way to protect their children’s development. Many parents cannot afford appropriate private services for their children if the school system fails to provide them, and even those with the means will be forced to resort to potentially lengthy and arduous dispute proceedings in order to recover their out-of-pocket expenses. *See School Comm. Burlington v. Dep’t Educ. Mass.*, 471 U.S. 359, 371-72 (1985). The Eleventh Circuit’s decision directly conflicts with the Third Circuit’s decision in *Pardini v. Allegheny Intermediate Unit*, 420 F.3d 181 (3d Cir. 2005), which not only protects children with autism during the critical window by guaranteeing their ability to continue receiving the services that parents and local agencies have already agreed are appropriate under Part C of the Act during the pendency of any dispute over the appropriateness of services the school system offers under Part B, but also serves to reduce the need or likelihood of costly and protracted disputes between parents and school districts that result when school districts unilaterally deny children with disabilities appropriate services.

Accordingly, *amicus curiae* Autism Speaks respectfully requests that this Court grant the petition in order to resolve the conflict between the Third and Eleventh Circuits on this issue of great importance, and to determine the rights of thousands of children

with autism and their families affected by the Eleventh Circuit's unnecessary and unjustified interpretation of their rights under the Act.

**I. FOR AN EVER-GROWING POPULATION OF CHILDREN DIAGNOSED WITH AUTISM SPECTRUM DISORDERS, A LAPSE IN APPROPRIATE SERVICES DURING THE WINDOW OF OPPORTUNITY WOULD BE DEVASTATING**

The devastating impact of autism is being experienced by an ever-growing number of families, as the incidence of autism spectrum disorder has risen dramatically in recent years. But even as more and more families come to understand the financial and emotional burdens of grappling with this disorder, a scientific consensus has developed that early, intensive educational services offer children the prospect of ameliorating and even overcoming the developmental deficits associated with autism.

With appropriate educational and related services, almost all children with autism can become more independent, and many can now claim realistic prospects for becoming self-sufficient. Some will even improve to the point where they appear indistinguishable from their non-disabled peers, participating in regular education classrooms alongside them. But these interventions are most effective when children with autism can be identified and served early; as children grow older, our ability to positively affect

their development diminishes. An inappropriate educational placement, then, can have a devastating impact on a child's future. Even if the child later receives appropriate services, potential for improvement will have irreversibly slipped away with the passing of time.

**A. As the Incidence of Autism Spectrum Disorder Has Mushroomed, Congress Increasingly Has Treated Autism as a National Priority**

In recent years, autism has grown dramatically more prevalent. In 1961, it was confidently asserted that “[i]nfantile autism is a relatively rare form of schizophrenia and is not important from an epidemiological point of view.” C.B. Ferster, *Positive Reinforcement and Behavioral Deficits of Autistic Children*, 32 CHILD DEVELOPMENT 437, 437 (1961), reprinted in CLASSIC READINGS IN AUTISM 53 (Anne M. Donnellan ed., 1985). Even in 1993,<sup>3</sup> shortly after the Department of Education began collecting statistics on autism, it classified only 19,058 children between 6 and 21 as having autism. 2 OFFICE OF SPECIAL EDUC. AND REHABILITATIVE SERVS., DEP’T OF EDUC., 26TH ANNUAL (2004) REPORT TO CONGRESS ON THE IMPLEMENTATION OF

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<sup>3</sup> Autism was added as a specifically-identified category of disability under IDEA by the Education of the Handicapped Act Amendments of 1990, Pub. L. 101-476, § 101, 104 Stat. 1103 (1990). It is very difficult to determine the prevalence of autism before the 1990s.

THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT 25 (2006).<sup>4</sup> But in 2005, the Department of Education reported 192,643 autistic students between the ages of 6 and 21 – a more than tenfold increase. Office of Special Education and Rehabilitative Services, Office of Special Education Programs, U.S. Department of Education, Data Analysis System (DANS), 1976-2005, *Table 1-3, Students ages 6 through 21 served under IDEA, Part B, by disability category and state: Fall 2005*.<sup>5</sup> The Centers for Disease Control report rates as high as 1 in every 150 children. Catherine Rice, *Prevalence of Autism Spectrum Disorders – Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2002*, 56 MORBIDITY AND MORTALITY WEEKLY REPORT SS-1, 12 at 12 (Feb. 9, 2007) (“CDC, 14 Sites Study”).<sup>6</sup> With some 24,000 children with autism born each year, S. REP. NO. 109-318 at 3 (2006), autism spectrum disorder is now more common among children than Down syndrome, diabetes, cancer, cystic fibrosis, hemophilia, and sickle cell disease.<sup>7</sup>

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<sup>4</sup> Available at <http://www.ed.gov/about/reports/annual/osep/2004/26th-vol-2.pdf> (accessed December 9, 2007).

<sup>5</sup> Available at [http://www.ideadata.org/tables29th/ar\\_1-3.xls](http://www.ideadata.org/tables29th/ar_1-3.xls) (accessed December 9, 2007).

<sup>6</sup> Available at <http://www.cdc.gov/mmwr/PDF/ss/ss5601.pdf> (accessed December 9, 2007).

<sup>7</sup> Figures available from the National Institutes of Health’s National Human Genome Research Institute, <http://www.genome.gov/10001204> (Down, cystic fibrosis, hemophilia, sickle cell disease), <http://ndep.nih.gov/diabetes/youth/youth.htm> (diabetes),

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As the incidence of autism has grown, Congress increasingly has made autism research and education a national priority. Autism was specifically identified as a disability under IDEA in 1991. *See* 20 U.S.C. § 1401(3)(a)(i); Education of the Handicapped Act Amendments of 1990, Pub. L. 101-467, Title I, § 101, Title IX, § 901(b)(10) to (20), 104 Stat. 1103 (1990). The Children's Health Act of 2000 directed the National Institutes of Health to expand and intensify autism research and mandated the creation of an Interagency Autism Coordinating Committee to coordinate autism research and other efforts within the Department of Health and Human Services. Pub. L. 106-310, Title I, 114 Stat. 1101 (2000). In 2004, IDEA was amended to encourage the Department of Education to support programs to train special education teachers in autism disorders, 20 U.S.C. § 1462(b)(2)(G), and programs providing technical assistance and in-service training to schools and personnel servicing children with autism spectrum disorders, 20 U.S.C. § 1463(c)(8)(D). *See* Individuals with Disabilities Education Improvement Act of 2004, Pub. L. 108-446, Title I, 118 Stat. 2647, 2677 & 2682 (2004). Most recently, Congress enacted the Combating Autism Act of 2006 to, among other things, dramatically increase funding for autism research, detection and intervention and to promote

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and [http://seer.cancer.gov/csr/1975\\_2004/results\\_merged/sect\\_28\\_childhood\\_cancer.pdf](http://seer.cancer.gov/csr/1975_2004/results_merged/sect_28_childhood_cancer.pdf) (cancer) (all sites accessed Dec. 10, 2007).

interagency coordination of autism-related activities through the NIH. See Combating Autism Act of 2006, Pub. L. 109-416, 120 Stat. 2821 (2006); S. REP. NO. 109-318 at 18-20.

**B. With Appropriate and Sustained Educational and Related Services, the Developmental Deficits Associated with Autism Can Be Ameliorated or Overcome**

Autism is a spectrum disorder encompassing a range of developmental disorders related to impaired social function, impaired communication and repetitive, stereotyped behaviors. The degree and manifestation of impairments can vary dramatically from individual to individual, and the spectrum of disorders includes Asperger's Disorder and Pervasive Developmental Disorder, Not Otherwise Specified ("PDD-NOS"). See DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS, FOURTH EDITION, TEXT REVISION at 69-75 (4th ed. 2000) ("DSM-IV-TR"); S. REP. NO. 109-318, 2-3 (Aug. 3, 2006). Most children with autism show an "inability to relate themselves in the ordinary way to people and situations from the beginning of life. . . ." Leo Kanner, *Autistic Disturbances of Affective Contact*, 2 *Nervous Child* 217 (1943), reprinted in CLASSIC READINGS IN AUTISM, at 41 (Anne M. Donnellan ed., 1985) (emphasis omitted). Impaired communication is another classic symptom of autism. Approximately 40 percent of children with autism do not talk, and others have difficulty learning to use language for communicative purposes.

S. REP. NO. 109-318 at 2; DSM-IV-TR at 70. Many children with autism also demonstrate restricted and stereotypical patterns of behavior or interests, an insistence on predictability, and great difficulty coping with unexpected changes to their routine. S. REP. NO. 109-318 at 3; DSM-IV-TR at 71.

The symptoms of autism generally manifest early, usually before the child's third birthday and possibly at eighteen months or earlier; in some cases symptoms are present almost from birth. S. REP. NO. 109-318 at 3, 9; NATIONAL INSTITUTES OF HEALTH, DEPARTMENT OF HEALTH AND HUMAN SERVICES, AUTISM SPECTRUM DISORDERS: PERVERSIVE DEVELOPMENTAL DISORDERS 2 (2007) ("NIH PDD").<sup>8</sup> The National Institute of Mental Health has identified a number of indicators of autism spectrum disorders that manifest before age three, including inability to point or make meaningful gestures, speaking words or combining words. *Id.* at 5. When diagnosing children with autism, "clinicians rely on behavioral characteristics . . . [which] may be apparent in the first few months of a child's life, or they may appear at any time during the early years. For the diagnosis, problems in at least one of the areas of communication, socialization, or restricted behavior must be present *before the age of 3.*" *See id.* at 12 (emphasis added).

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<sup>8</sup> Available at <http://www.nimh.nih.gov/health/publications/autism/nimhautismspectrum.pdf> (accessed Dec. 10, 2007).

While the cause or causes of autism are still unclear, there is broad agreement that, if properly diagnosed at a young age, the symptoms of autism often can be significantly ameliorated through appropriate educational interventions. As discussed below, with appropriate, consistent and *early* intervention – as soon as possible, while the child’s developing brain has the greatest degree of “neurologic plasticity” – it is possible for most children to make significant progress in communication, adaptive behaviors, and socialization. See, e.g., Tristram Smith and O. Ivar Lovaas, *Intensive and early behavioral intervention with autism: the UCLA young autism project*, 10 *INFANTS & YOUNG CHILD*. 67-78 (1998). Appropriate education offers the possibility that children with autism can achieve self-sufficiency and become functioning, contributing members of society rather than permanent financial and emotional burdens on their families and on the public treasury.<sup>9</sup>

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<sup>9</sup> For descriptions of autistic children who have grown into productive – even remarkable – adults, see, e.g., OLIVER SACKS, *AN ANTHROPOLOGIST ON MARS* 244-296 (1995); CLARA CLAIBORNE PARK, *EXITING NIRVANA* (2001); STEPHEN M. SHORE, *BEYOND THE WALL* (2001); KAMRAN NAZEER, *SEND IN THE IDIOTS* (2006).

**C. Taking Advantage of the “Window of Opportunity” is Critical to a Child’s Ability to Remediate or Overcome the Symptoms of Autism**

There is “abundant scientific evidence” that early, intensive instruction “can result in dramatic improvements for children with autism: successful integration in regular schools for many, *completely normal functioning* for some.” Gina Green, *Early Behavioral Intervention for Autism*, in BEHAVIORAL INTERVENTION FOR YOUNG CHILDREN WITH AUTISM: A MANUAL FOR PARENTS AND PROFESSIONALS 29, 29 (Catherine Maurice et al. eds., 1996) (emphasis in original). Over the course of the last two decades “virtually every study” has found that early and intensive intervention is effective, and there is now “little doubt” that appropriate intervention “can produce large, comprehensive, lasting and meaningful improvements in many important domains for a large proportion of children with autism.” *Id.* at 38.<sup>10</sup>

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<sup>10</sup> See Geraldine Dawson and Julie Osterling, *Early intervention in autism*, in THE EFFECTIVENESS OF EARLY INTERVENTION 307, 314 (1997) (reviewing eight model early intervention programs and finding that “all of the programs were quite effective in fostering positive school placements, significant developmental gains, or both for a substantial percentage of their students”); Tristram Smith et al., *Intensive behavioral treatment for preschoolers with severe mental retardation and pervasive developmental disorder*, 102 AM. J. MENT. RETARD. 238, 238 (1997) (preschool children who received intensive behavioral treatment “made major increases in intellectual, academic, adaptive, and socioemotional functioning”); *id.* at 246-47 (preschool  
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children who received intensive behavioral treatment scored in the average range on standardized intelligence tests and performed satisfactorily in regular classes several years after the treatment, compared to only 2.5% of autistic children who received minimal treatment); John J. McEachin et al., *Long-term outcome for children with autism who received early intensive behavioral treatment*, 97 AM. J. MENT. RETARD. 359, 367-68 (1993) (autistic children who received early and intensive behavioral intervention prior to age 4 for a period of approximately 2-3 years preserved their gains in intellectual and educational functioning at an average age of 13 years, and had average IQ scores 30 points higher than that of control subjects); Sandra L. Harris et al., *Changes in cognitive and language functioning of preschool children with autism*, 21 J. AUTISM DEV. DISORD. 281, 287 (1991) (IQ scores of young children increased an average of nearly 19 points after one year of intensive education); Sally J. Rogers and Hal Lewis, *An effective day treatment model for young children with pervasive developmental disorders*, 28 J. AM. ACAD. CHILD & ADOLESC. PSYCHIATRY 207, 207 (1989) (6 months of intensive intervention resulted in significant gains “in cognition, perpetual/fine motor, social/emotional, and language skills, which were maintained or increased over a 12- to 18-month treatment.”); O. Ivar Lovaas, *Behavioral treatment and normal educational and intellectual functioning in young autistic children*, 55 J. CONSULT. & CLIN. PSYCHOL. 3, 7-9 (1987) (47% of autistic children who received intensive behavioral intervention achieved normal-range IQ scores and successful performance in public schools, compared with only 2% of autistic children who received less intensive intervention); see generally Committee on Children With Disabilities, American Academy of Pediatrics, *Technical Report: The Pediatrician’s Role in the Diagnosis and Management of Autistic Spectrum Disorder in Children*, 107:5 PEDIATRICS 85 (May 2001), available at <http://pediatrics.aappublications.org/cgi/content/full/107/5/e85> (accessed Dec. 10, 2007).

Indeed, education is the primary treatment for autism.<sup>11</sup>

But the effectiveness of intervention depends on early application. Leading federal agencies, professional organizations and educational institutions all have stressed the importance of early intervention for children with autism.<sup>12</sup> Congress likewise has emphasized

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<sup>11</sup> See NAT'L RESEARCH COUNCIL, EDUCATING CHILDREN WITH AUTISM 12 (2001) ("Education . . . is currently the primary form of treatment in autism."); Green, *supra*, at 29 (whereas the effectiveness of early, intensive instruction in treating autism has repeatedly been shown, "[n]o other treatment for autism offers comparable evidence of effectiveness.") (citations omitted); Smith & Lovaas, *supra*, at 68 (educational approaches to the treatment of autism have been empirically validated, but biomedical interventions "appear to do little to alter the outcomes of individuals with autism."); Lovaas, *supra* note 12, at 3 ("Medically and psychodynamically oriented therapies have not proven effective in altering outcome.").

<sup>12</sup> See NIH PDD at 17 ("One point that most professionals agree on is that early intervention is important."); NAT'L INST. OF MENTAL HEALTH, DEP'T OF HEALTH AND HUMAN SERVS., REPORT TO CONGRESS ON AUTISM 2 (2006) ("Early intervention is critical for affected children to gain maximum benefit from current therapies."), available at [http://www.nimh.nih.gov/research-funding/scientific-meetings/recurring-meetings/iacc/reports/autismreport\\_fy2005.pdf](http://www.nimh.nih.gov/research-funding/scientific-meetings/recurring-meetings/iacc/reports/autismreport_fy2005.pdf) (accessed Dec. 10, 2007); Joicey Hurth et al., *Areas of agreement about effective practices among programs serving young children with autism spectrum disorders*, 12 INFANTS & YOUNG CHILD. 17, 21-26 (1999) (discussing general consensus that "[c]hildren who begin appropriate services earlier have better out-comes" and that the "earliest possible start to intervention" is an integral or defining part of the program); Nat'l Research Council, *supra* note 11, at 6 ("The committee recommends that educational services begin as soon as a child is suspected of having an autistic spectrum disorder."); see generally American Academy

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that “children with autism spectrum disorder identified early and enrolled in early intervention programs show significant improvements in their language, cognitive, social, and motor skills, as well as in their future educational attainment and decreased needs for special education services.” S. REP. NO. 109-318 at 10. Intervention “should begin as soon as possible, preferably in the preschool years, because young children have not yet fallen as far behind their typically developing peers and may have more neurologic plasticity than older children.” Smith & Lovaas, *supra*, at 68-69. During this period “the young, developing brain is very modifiable,” Green, *supra*, at 39; and “rigorous behavioral therapy modifies the neural circuitry before the condition becomes permanent.” LYNN M. HAMILTON, *FACING AUTISM* 92 (2000) (citations omitted); *see also* McEachin et al., *supra* note 12, at 371 (“[A]lterations in neurological structure are quite possible as a result of changes in the environment in the first years of life” and “intensive early intervention could compensate for neurological anomalies in such children.”).

Indeed, Congress enacted Part C of the IDEA precisely because it recognized the importance of

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of Pediatrics, *supra* note 12. *See also* Cathryn Garland and Michael O’Hanlon, *Studying Autism Isn’t Enough*, N.Y. TIMES (Nov. 21, 2006) (“There is broad consensus, as reflected in previous studies by the National Academy of Sciences and American Academy of Pediatrics, that early and intensive intervention is critical.”), available at <http://www.nytimes.com/2006/11/21/opinion/21ohanlon.1.html> (accessed Dec. 10, 2007).

early intervention for children with disabilities. When Congress required early intervention services for children under the age of 3, *see* 20 U.S.C. § 1432(5), it expressly found an “urgent and substantial need . . . to enhance the development of infants and toddlers with disabilities, to minimize their potential for developmental delay, and to recognize the significant brain development that occurs during a child’s first 3 years of life.” *See* 20 U.S.C. § 1431(a)(1). Many thousands of families around the country have availed themselves of early intervention services under this provision. U.S. Department of Education Data shows that approximately 293,000 infants and toddlers around the country were receiving early intervention services as of the end of 2005. *See* DANAHER, J., GOOD, S & LAZARA, A. (EDS.), PART C UPDATES (9TH ED.) AT 92, CHAPEL HILL: THE UNIVERSITY OF NORTH CAROLINA, FPG CHILD DEVELOPMENT INSTITUTE, NATIONAL EARLY CHILDHOOD TECHNICAL ASSISTANCE CENTER (“NECTAC Part C Update”).<sup>13</sup> Nearly 108,000 infants and toddlers transitioned out of the Part C program during the 2004-05 reporting year because they became eligible to transition to educational services provided by school districts under Part B. *Id.* at 122.

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<sup>13</sup> Available at <http://www.nectac.org/~pdfs/pubs/partcupdate2007.pdf> (accessed Dec. 10, 2007).

Children with autism cannot make up for lost time. When the opportunity presented during this narrow window passes, the squandered potential cannot be regained later. “[B]oth popular literature and professional literature offer promises of positive development outcomes, even ‘cure’ or remediation of autistic symptoms, given early and intensive intervention. Families’ desire for best outcomes is heightened by the threat that untreated, or inadequately treated, the syndrome can have devastating developmental impacts.” Hurth et al., *supra* note 12, at 18. As the child grows older, he or she will “have a far more difficult time learning the skills that he needs to function in life.” *J.H. ex rel. J.D. v. Henrico County Sch. Bd.*, 326 F.3d 560, 565 (4th Cir. 2003).<sup>14</sup>

Accordingly, losing part of this “valuable and unretrievable time” could well be irreparable. *Noyes v. Grossmont Union High Sch. Dist.*, 331 F. Supp. 2d

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<sup>14</sup> See also *Jaynes v. Newport News Sch. Bd.*, No. 4:99cv146, 2000 U.S. Dist. LEXIS 21684, at \*1-2 (E.D. Va. Sept. 7, 2000), *aff’d*, 13 Fed. Appx. 166 (4th Cir. July 10, 2001) (neurologist testimony that “there’s a window of opportunity and that window of opportunity is greatest between the age of discovery and as early as possible;” parents should “immediately, immediately do something fast, now, right now”); Anahad O’Connor, *In Autism, New Goal Is Finding It Soon Enough to Fight It*, N.Y. TIMES (Dec. 14, 2004) (“After a certain point, you can still teach an autistic child certain things, ameliorate destructive behaviors, but you’re not really going to change the developmental pathway that they’re on.”) (quotation omitted), available at <http://www.nytimes.com/2004/12/14/health/14/auti.html> (accessed Dec. 10, 2007).

1233, 1243 (S.D. Cal. 2004) (internal citations and quotations omitted), *rev'd sub nom.*, *Evans v. Grossmont Union High Sch. Dist.*, Nos. 04-56341 & 04-56360, 197 Fed. Appx. 648 (9th Cir. Aug. 15, 2006). “Children with autism have a profound ability to regress,” and if intensive treatment is not maintained consistently, “you have to go back and reinvent the wheel, not completely, not from the ground up, but you are going to have to go back and basically retool.” *J.H. ex rel. J.D. v. Henrico County Sch. Bd.*, 395 F.3d 185, 190 (4th Cir. 2005) (quoting expert testimony). *See also* PATRICIA PRELOCK, *AUTISM SPECTRUM DISORDERS: ISSUES IN ASSESSMENT AND INTERVENTION* 354 (2006) (“A child with [autism spectrum disorder] has significant difficulties that will require intensive and ongoing intervention to ensure progress and prevent regression.”).

Young children with autism already receiving services that parents and local agencies have agreed are appropriate under Part C of the Act cannot afford to lose this valuable and irretrievable time during a dispute over the availability or appropriateness of services under Part B. The younger the child, the wider the window of opportunity when appropriate interventions are most important, and the more critical parents’ need to be able to maintain the child’s current placement during any dispute with the school system. Indeed, the importance of IDEA’s pendency provision is even more important for young children in transition from Part C to Part B than it is for older children already covered by Part B. Parents should

not be forced to watch as their young children's early intervention services lapse (or are materially reduced) when every passing moment erodes potential benefits that can never be regained. For these children and their parents, "every moment counts." Laurie Tarkan, *Autism Therapy Is Called Effective, but Rare*, N.Y. TIMES, Oct. 22, 2002<sup>15</sup> (describing the "horrible feeling of time slipping away and nothing being done" when parents of children with autism don't have access to appropriate treatment); see also *County Sch. Bd. of Henrico County v. R.T.*, 433 F. Supp. 2d 692, 696 (E.D. Va. 2006) ("a critical window of developmental opportunity was closing" for a child who was not receiving an adequate public education). "Children with autism can't afford to waste a second. . . . With the right kind of early intervention, they can learn. Without it, there's no hope." Leslie C. Feller, *When Autistic Child's Growth Is at Stake*, N.Y. TIMES, Apr. 25, 1999 (internal quotation omitted).<sup>16</sup>

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<sup>15</sup> Available at <http://query.nytimes.com/gst/fullpage.html?sec=health&res=9C05E0D71F3DF931A15753C1A9649C8B63> (accessed Dec. 10, 2007).

<sup>16</sup> Available at <http://query.nytimes.com/gst/fullpage.html?sec=health&res=9503E2D9143AF936A15757C0A96F958260> (accessed Dec. 10, 2007).

## **II. MANY PARENTS CANNOT AFFORD THE FINANCIAL BURDEN OF APPROPRIATE, PRIVATE EDUCATIONAL SERVICES DURING THE PENDENCY OF A DISPUTE**

Under the Eleventh Circuit's decision below, parents of young children with autism facing a dispute with the school system over appropriate educational and related services for their child – or even whether their child should receive any services at all – have only one means for ensuring their child's continued access to appropriate services: securing those services themselves, at their own personal expense. This is an option that any parent with the means to do so would exercise, rather than put their child's future at risk in an inappropriate placement. But forcing parents to shoulder the full financial impact of a school district's inability or unwillingness to provide appropriate services under Part B would be crushing for most families, and flatly unaffordable for many.

The financial burdens of raising a child with autism can be immense. Private service providers can cost up to \$50,000 a year or more. THE BROOKINGS INST. AND THE HELP GROUP, CONFERENCE REPORT: AUTISM AND HOPE at 5 (2006).<sup>17</sup> The median income for

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<sup>17</sup> Available at [http://www.brookings.edu/comm/conference\\_report/20051216autism.pdf](http://www.brookings.edu/comm/conference_report/20051216autism.pdf) (accessed Dec. 10, 2007).

an American household in 2005, in comparison, was \$46,326. U.S. CENSUS BUREAU, U.S. DEPT OF COMMERCE, INCOME, POVERTY, AND HEALTH INSURANCE COVERAGE IN THE UNITED STATES: 2005, at 5 (2006).<sup>18</sup> Services for children with autism are rarely covered by private health insurance, even assuming the parents are insured. See AUTISM SPECTRUM DISORDER EXPERT WORKING GROUP, INTERAGENCY AUTISM COORDINATING COMMITTEE, NATIONAL INSTITUTE OF MENTAL HEALTH, DEPARTMENT OF HEALTH AND HUMAN SERVICES, AUTISM SPECTRUM DISORDERS ROADMAP 16 (May 16, 2005);<sup>19</sup> Milt Freudenheim, *Battling Insurers Over Autism Treatment*, N.Y. TIMES, Dec. 21, 2004.<sup>20</sup> If both parents work, one parent often goes part-time or quits entirely to devote more time to raising the child – magnifying the financial impact of raising a child with autism. See, e.g., Stephanie Rosenblum, *The Neediest Cases: Putting Their Son, Who Is Autistic, First*, N.Y. TIMES, Jan. 15, 2005;<sup>21</sup> John O’Neil, *One Boy’s Journey Out Of Autism’s Grasp*, N.Y. TIMES,

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<sup>18</sup> Available at <http://www.census.gov/prod/2006pubs/p60-231.pdf> (accessed Dec. 10, 2007).

<sup>19</sup> Available at <http://www.nimh.nih.gov/research-funding/scientific-meetings/recurring-meetings/iacc/expert-working-group-on-services-report-to-the-iacc-services-subcommittee.pdf> (accessed Dec. 10, 2007).

<sup>20</sup> Available at <http://www.nytimes.com/2004/12/21/business/21autism.html> (accessed Dec. 10, 2007).

<sup>21</sup> Available at <http://query.nytimes.com/gst/fullpage.html?res=990DEFDF1538F936A25752C0A9639C8B63> (accessed Dec. 10, 2007).

Dec. 29, 2004.<sup>22</sup> A child with autism is a gift and a joy, but there is no denying that the additional monetary and emotional costs of raising a child with autism can weigh heavily on the family. NAT'L RESEARCH COUNCIL, *supra* note 11, at 33-35; *see also* Victoria Clayton, *How Families Connect to Cope with Autism*, MSNBC.com, Feb. 24, 2005 ("Besides the anxiety and the high demands on parents' time and energy, autism can also take a heavy toll on family finances and put a big strain on relationships.").<sup>23</sup>

Even parents who may manage to come up with the means to fund private services face the prospect of lengthy dispute proceedings before they can recover their out-of-pocket expenses. *School Comm. Burlington v. Dep't Educ. Mass.*, 471 U.S. 359, 370 (1985). But the many parents who cannot afford private services have no choice but to accept the school district's proposed services (if any) until they can challenge them through the Act's often-lengthy administrative and judicial proceedings – all the while watching their child's window of opportunity drawing ever-nearer to closed. Because the damage to a child's potential for progress during this window is irreparable, these parents are left without any remotely adequate remedy and the Act's primary purpose of ensuring a "floor of opportunity" for children

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<sup>22</sup> Available at <http://www.nytimes.com/2004/12/29/education/29autism.html> (accessed Dec. 10, 2007).

<sup>23</sup> Available at <http://www.msnbc.com/id/6988852/> (accessed Dec. 10, 2007).

with disabilities is eviscerated. *Board of Educ. v. Rowley*, 458 U.S. 176, 201 (1982).

**III. THIS COURT SHOULD GRANT *CERTIORARI* TO RESOLVE THE SPLIT BETWEEN THE THIRD AND ELEVENTH CIRCUITS AND TO PRESERVE THE RIGHTS OF CHILDREN WITH AUTISM TO CONSISTENCY OF SERVICES DURING THE WINDOW OF OPPORTUNITY**

The Court should grant the petition in order to resolve the split between the Third and Eleventh Circuits on this issue of great importance to young children with autism and their families. As the discussion above illustrates, young children with autism are in a critical developmental window during their transition from services under Part C of the Act to services under Part B of the Act. Continuity of appropriate and effective interventions during this transition is absolutely essential to the chances for children with autism to progress, to remediate the core symptoms of autism, and potentially even to overcome those symptoms and join their peers in regular education classrooms. For young children with autism already receiving appropriate services – agreed to both by parents and local agencies under Part C of the Act – the risk that this window of opportunity will be squandered during a dispute with a school system over appropriate services under Part B of the Act is grave. Many parents will have no alternative but to accept the school system’s inappropriate services (if

any are offered at all) while potentially lengthy dispute proceedings are played out, with no remedy for the harm to their child's developmental potential.

The Eleventh Circuit's decision is not required by the language of the Act, is contrary to Congressional purpose in enacting Part C, threatens to pull the "basic floor of opportunity" from underneath young children with disabilities at the most harmful juncture, and conflicts with the Third Circuit's decision in *Pardini v. Allegheny Intermediate Unit*, 420 F.3d 181 (3d Cir. 2005). Under the Third Circuit's sensible decision, the rights of parents and their children with disabilities under the Act are protected and their ability to capitalize on the critical window of opportunity is preserved. Moreover, there will be less cause for lengthy and burdensome adversarial proceedings between parents and school systems: those parents who could afford it will have fewer claims for reimbursement of private educational services if their children's current, appropriate placement is protected by the pendency provision during the course of a dispute with the school district; and it is reasonable to expect that school districts will be more likely to propose appropriate services in the first instance if they cannot unilaterally force the child into inappropriate placements or deny them services altogether.

In light of the split of authority on this issue of great importance to thousands of young children with

autism across this nation and their families, the petition should be granted.



**CONCLUSION**

For the foregoing reasons, *amicus curiae* Autism Speaks respectfully requests that the Court grant certiorari to Petitioners and reverse the Judgment of the Eleventh Circuit.

Respectfully submitted,

GARY S. MAYERSON  
Director, Autism Speaks  
Federal Legal  
Appeals Project

MAYERSON & ASSOCIATES  
330 West 38th Street  
Suite 600  
New York, New York 10018  
(212) 265-7200

*Co-counsel for Amicus Curiae  
Autism Speaks*

ROBERT H. PEES  
*Counsel of Record*

MICHAEL D. LOCKARD  
EVANDRO C. GIGANTE

AKIN GUMP STRAUSS HAUER  
& FELD LLP  
590 Madison Avenue  
New York, New York 10022  
(212) 872-1000

*Counsel for Amicus Curiae  
Autism Speaks*