No. 04-698

IN THE

Supreme Court of the United States

BRIAN SCHAFFER, A MINOR, BY HIS PARENTS AND NEXT FRIENDS, JOCELYN AND MARTIN SCHAFFER, *ET AL.*,
Petitioners,

v.

JERRY WEAST, SUPERINTENDENT OF MONTGOMERY COUNTY PUBLIC SCHOOLS, *ET AL.*,
Respondents.

On Writ of Certiorari
to the United States Court of Appeals
for the Fourth Circuit

BRIEF OF VARIOUS AUTISM ORGANIZATIONS AS *AMICI CURIAE* IN SUPPORT OF PETITIONERS

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QUESTION PRESENTED

Under the Individuals with Disabilities Education Act, when parents of a disabled child and a local school district reach an impasse over the child's individualized education program, either side has a right to bring the dispute to an administrative hearing officer for resolution. At the hearing, which side has the burden of proof—the parents or the school district?

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STATEMENT OF INTEREST[*]

The Individuals with Disabilities Education Act ("IDEA" or "Act"), 20 U.S.C. § 1400 *et seq.*, provides federal money to assist state and local agencies in educating children with handicaps. To qualify for this program of federal assistance, a State must demonstrate, through a detailed plan submitted for federal approval, that it has in effect a policy that assures all eligible children the right to a "free appropriate public education" tailored to the unique needs of the child by means of an "individualized educational program" (IEP). *See* 20 U.S.C. § 1412(a)(2), (4). The model for the creation of an IEP is a collaborative decision-making process between schools and parents, *see*, *e.g.*, 34 C.F.R. § 300.501(a)-(c) (2004), but when the parties reach an impasse, the parents may request "an impartial due process hearing" to resolve the matter. *See* 20 U.S.C. § 1415(b)(6), (f); 34 C.F.R. §§ 300.507-.512 (2004).

The IDEA's definition of "children with disabilities" includes, among its categories, children with autism. 20 U.S.C. § 1401(3)(A). Children with autism are unquestionably the fastest-growing segment of the IDEA-covered population: In 1993, the number of children diagnosed with autism, and thus covered by the IDEA, was approximately 20,000; by 2002, that number had increased sixfold, to almost 120,000. United States Government Accountability Office, *Report to the Chairman and Ranking Minority Member, Subcommittee on Human Rights and Wellness, Committee on Government Reform, House of*

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[*] No party other than *amici* and their counsel authored this brief in whole or in part, and no person or entity, other than *amici* and their counsel, has made a monetary contribution to the preparation or submission of this brief. Both parties have granted consent to the filing of this *amici curiae* brief. Letters of consent are on file with the Clerk of the Court.

Representatives: Special Education, Children with Autism, GAO-05-220 at 17 (Jan. 2005).

Amici, listed below in alphabetical order, are nonprofit organizations dedicated to promoting and supporting the interests of children with autism and their families. The mission of *amicus* Autism Society of America, Northern Virginia Chapter (ASA-NV) is to promote lifelong access and opportunity for all individuals with autism and their families, in an effort to enable them to be fully participating members of their communities. Education, advocacy at state and federal levels, active public awareness and the promotion of research all form the cornerstones of ASA-NV's efforts to carry forth its mission. The growing membership base of ASA-NV encompasses a broad and diverse group of parents, family members, special education teachers, administrators, medical doctors, therapists, nurses and aides, as well as countless other personnel involved in the education, care, treatment and support of individuals with autism in the Northern Virginia area, which has one of the fastest growing populations of children with autism in the United States. Recognizing and respecting the diverse range of opinions, needs and desires of this group, ASA-NV embraces an overall philosophy which chooses to empower individuals with autism, their parents or caregivers, in order to enable them to make choices best suited to the needs of the person with autism. This brief is being filed with the full support and approval of the Autism Society of America.

Amicus Parents for Autistic Children's Education (PACE™) is a not-for-profit membership organization that is open to parents and guardians of children with autism or similar disorders in the Northern Virginia area. PACE™ advocates on behalf of children with autism and their families for high-quality, effective, and scientifically based educational programs and to ensure school-system compliance with the IDEA. In doing so, PACE™ seeks to educate parents, the public, and governmental leaders on a wide range of issues related to the special needs of these children and, since its founding, has represented over 300 families who have children with developmental disabilities. Among other accomplishments, PACE™ was instrumental in developing an Applied Behavior Analysis (ABA) pilot program for preschool children with autism in Fairfax County in 1998; more recently, in 2003, it proposed the establishment of Virginia's first charter school for children with autism.

Amicus Parents Of Autistic Children of Northern Virginia (POAC-NoVA), Inc., is a non-profit membership organization that works to improve the quality and quantity of education for students with autism within the Fairfax County Public School (FCPS) system and surrounding area. In addition to monthly support groups covering many topics related to special education issues as well as an active internet support system, POAC-NoVA hosts workshops throughout the year providing access to expert therapy and teaching curriculum for autism and related disorders. Attendance is typically representative of every major school system in the Washington, D.C. Metropolitan Area, and the workshops often qualify for teacher recertification credit due to POAC-NoVA's constant school advocacy. POAC-NoVA's recent school advocacy efforts were largely responsible for the Fairfax County (Virginia) School Board's approval of the new, enhanced autism program for an estimated 600 students with autism in the pre-school through elementary grades starting with the 2004-2005 school year, including an unprecedented $3 million allocated for hiring and training additional educators specifically for this new program. POAC-NoVA continues to be a primary non-profit organization working with the FCPS staff to ensure that parental concerns for the new enhanced autism program are heard and understood.

Amicus Unlocking Autism (UA) is a not-for-profit organization founded primarily for the purpose of increasing awareness about autism. Through awareness, UA strives to help those on the autism spectrum reach their greatest potential in leading fulfilling and productive lives in relationships, society and employment. UA seeks to increase society's ability to work with and understand people with autism, as well as to raise funds for critical biomedical and behavioral research into autism. In an effort to increase public awareness of autism, in 1999 UA launched the "Open Your Eyes" project, which is a collection of photographs of children with autism designed to put a real face on the disorder. For parents of children with autism, UA provides information about biomedical treatment, behavioral therapies, pending legislation and existing laws. In addition, UA has developed an international network of parents and professionals to assist the parents of newly diagnosed children in finding available resources and support in their immediate area.

Because the Court's decision in this case will have profound effects on how IEP disputes between parents and schools will be resolved, *amici* and the constituencies they represent and support have a special interest in participating in the debate over where the burden of proof should lie in IEP proceedings. In addition, *amici* hold a special position in the community of individuals served and affected by the IDEA, and are uniquely suited to provide the Court with what *amici* believe will be helpful insights into the daily lives of families dealing with the special challenges of autism.

SUMMARY OF ARGUMENT

I. The allocation of the burden of proof in the IEP due process hearing goes to the very heart of IDEA's mandate that children with disabilities be provided a "free appropriate public education." The holding of the panel majority in the Fourth Circuit—which simply allocated the burden of proof upon the party seeking relief—did not properly take account of basic notions of policy and fairness inherent in both the allocations of burdens and the provision of special education. This Court's own pronouncements on the special role of the

IDEA, its objectives and its history, and the general allocation of burdens in focused statutory settings, counsel a functional interpretation of the Act in line with the stated Congressional objectives and the overall mission of the statute. *Amici* urge that the burden of proof in an IEP due process hearing should be placed squarely upon the party with the exclusive means of knowledge, the ability to efficiently advance judicial review proceedings, and statutory obligation to realize the objectives of the Act, which is the school system.

II. This result also acknowledges the realities of raising a child with autism. Children with autism have been characterized as "precisely the children IDEA seeks to protect and who states and localities should serve." *See* President's Commission on Excellence in Special Education, *A New Era: Revitalizing Special Education for Children and Their Families* 30 (2002) (available at http://www.ed.gov/inits/commissionsboards/whspecialeducation) (hereinafter "*President's Commission*"). As the fastest-growing and most widely diagnosed developmental disability in the nation—affecting 1 in every 166 children—it is still one of the least-understood childhood impairments, leaving parents and families of children with autism to face a number of difficult realities unique to raising such a child. From differential diagnoses to fleeting windows of opportunity for learning essential skills, raising a child with autism imposes upon parents the duty to educate themselves, advocate for better understanding and education, and sustain a functioning family in the face of constantly escalating strains on their time, energy, and finances. Allocating the burden of proof to school districts will sensibly, and equitably, contribute to furthering the Congressional design while avoiding the allocation of an additional, legal burden to parents with plenty of non-legal ones to carry.

ARGUMENT

I. THE STATUTORY REQUIREMENTS OF THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT, ITS SPECIFIC GOALS, AS WELL AS BASIC CONSIDERATIONS OF POLICY, CONVENIENCE, AND FAIRNESS, ALL COMPEL THE CONCLUSION THAT THE BURDEN OF PROOF IN IEP PROCEEDINGS SHOULD BE PLACED ON THE SCHOOL SYSTEM

The choice before this Court—whether the burden of proof in IEP proceedings should be placed on the school or on the parents—could be reduced to an abstract, academic debate. But for *amici,* their members, and the constituencies they serve, the issue in this case is anything but academic. Rather, it goes straight to the heart of IDEA's guarantee that all children, including those with autism or other disabilities, will receive a "free appropriate public education" from the schools in their communities. And, as Section II, below, amplifies, if the burden were put upon the parents, as the Fourth Circuit's decision did here, the decision would have profound effects on the ability of these parents, already burdened by the special demands of raising a child with autism, to ensure that the schools provide their children with that appropriate education.

In this case, the panel majority in the Fourth Circuit gave dispositive weight to the notion that when "a statute is silent, the burden of proof is normally allocated to the party initiating the proceeding and seeking relief." Pet. App. 6 (citing 2 J. Strong, *McCormick on Evidence* § 337, at 411-12 (5th ed. 1999)). Though this is often stated as an "ordinary rule" or a "default rule," *see, e.g., Campbell v. United States*, 365 U.S. 85, 96 (1961), it is equally well recognized that "other factors such as policy considerations, convenience, and fairness may allow for a different allocation of the burden of proof." Pet. App. 6 (citing 2 *McCormick on*

Evidence § 337). These other factors were not appropriately weighted by the panel majority in the Court of Appeals.

Indeed, the so-called "default rule" of having the burden of proof follow the burden of pleading has been widely criticized. In Bruce L. Hay, *Allocating the Burden of Proof*, 72 Ind. L.J. 651 (1997) (cited in 2 *McCormick on Evidence* § 337, at 411 n.1), Professor Hay cautioned against blind adherence to the default rule of "plaintiff bears the burden," pointing out that many of the policy considerations that are regularly offered in support of the default rule can be used equally to support a "defendant bears the burden" rule. *See id.* at 656-57 ("It will not do, therefore, to argue that the burden of proof should be placed on the plaintiff because she is the one responsible for putting the legal machinery into motion. That criterion gives as much support for the opposite allocation."). The McCormick treatise itself embraces this critique, observing: "[L]ooking for the burden of pleading is not a foolproof guide to the allocation of the burdens of proof . . . reference to which party has pleaded a fact is no help at all . . . in a case of first impression." 2 *McCormick on Evidence* § 337, at 411-12.

That is undoubtedly why this Court has itself recently recognized that "[n]o 'single principle or rule . . . solve[s] all cases and afford[s] a general test for ascertaining the incidence' of proof burdens." *Alaska Dep't of Envtl. Conservation v. EPA*, 540 U.S. 461, 494 n.17 (2004) (citing 9 J. Wigmore, *Evidence* § 2486, at 288 (J. Chadbourn rev. ed. 1981)) (revisions in opinion). Rather, the allocation of the burden of proof must be made with a special sensitivity to the goals of the law in question, as well as policy considerations.

In the context of the IDEA, these goals and policies lead to the conclusion that the burden of proving that an IEP will provide the statutorily mandated "free appropriate public education" should be allocated to the school district responsible for providing that appropriate education. Several reasons, independently and collectively, compel this conclusion.

First, placing the burden of proof on the school district is more consistent with the special procedural context and operation of the IDEA. That Act establishes the IEP process as a joint and collaborative effort between school systems on the one hand, and parents and children on the other. *See, e.g.*, David M. Engel, *Law, Culture, and Children With Disabilities: Educational Rights and the Construction of Difference*, 1991 Duke L.J. 166, 170 (describing the IEP process as "controlled interaction between parents and educators") (citing H.R. Conf. Rep. No. 94-664, 94th Cong., 1st Sess. 43 (1975)). The goal is not for one side or the other to "win," but to reach a positive result for the child's education. *See, e.g.*, *Lascari v. Bd. of Educ. of Rampo-Indian Hills Reg'l High School Dist.*, 560 A.2d 1180 (N.J. 1989).

In *Campbell v. United States*, 365 U.S. 85 (1961), this Court addressed the allocation of burdens in the analogous context of non-adversarial proceedings mandated by statute. There, the trial court conducted a mandatory hearing without the jury present to determine whether a government "Interview Report" qualified as a "statement" required to be produced to the defendant under the Jencks Act, 18 U.S.C. § 3500. The district court placed on the criminal defendants the burden of subpoenaing the government investigator as "their witness" in order to support their request for the Interview Report. This Court rejected that allocation of the burden and held that, because of the non-adversarial nature of this proceeding, "the emphasis on the petitioners' burden to produce the evidence was misplaced." 365 U.S. at 95.

> The function of prosecution and defense at the inquiry was not so much a function of their adversary positions in the trial proper, as it was a function of their duty to come forward with relevant evidence which might assist the judge in the making of his determination. … The statute

> says nothing of burdens of producing evidence. Rather it implies the duty in the trial judge affirmatively to administer the statute in such way as can best secure relevant and available evidence necessary to decide between the directly opposed interests protected by the statute—the interest of the Government in safeguarding government papers from disclosure, and the interest of the accused in having the Government produce "statements" which the statute requires to be produced.

Id. Placing the burden on the government—even though it was not the moving party in the hearing—was considered proper because "the interest of the United States in a criminal prosecution . . . is not that it shall win a case, but that justice shall be done." *Id.* at 96 (internal quotation marks omitted).

Viewed in the light shed by *Campbell*, it would similarly be appropriate to put the burden of proof in IEP due process hearings on the school, whose interest, much like the government's interest in *Campbell*, is that a "free appropriate public education" "shall be done." Indeed, the school is assigned the affirmative obligation to provide that education in exchange for federal funding. *See* 20 U.S.C. § 1412(a)(1); Pet. App. 16 (Luttig, J., dissenting). In this situation, just as in *Campbell*, the party imposed with the statutory obligation—and given the means to meet that obligation—should bear the burden of proving that it indeed satisfied that obligation.

Second, placing the burden of proof on the school districts is more consistent with the goals of the Act, as illuminated by its history. The passage of the Education for All Handicapped Children Act, the precursor to the IDEA, "followed a series of landmark court cases establishing in law the right to education for all handicapped children." *Bd. of Educ. of Hendrick Hudson Cent. Sch. Dist. v. Rowley*, 458 U.S. 176, 192 (1982); S. Rep. No. 94-168, at 6, *reprinted in* 1975 U.S.C.C.A.N. 1425, 1430. The two "landmark" cases, *Mills v. Bd. of Educ.*, 348 F. Supp. 866, 881 (D.D.C. 1972), and *Pennsylvania Ass'n for Retarded Children v. Commonwealth*, 334 F. Supp. 1257 (E.D. Pa. 1971) and 343 F. Supp. 279, 305 (E.D. Pa. 1972), explicitly held that the Due Process and Equal Protection Clauses required school districts to bear the cost burden of providing an education, and the burden of proof in justifying an education, for all handicapped children. *See Mills*, 348 F. Supp. at 881, 882 (holding that "Defendants [the school system] shall bear the burden of proof as to all facts and as to the appropriateness of any disposition" or placement in the due process hearings ordered by the court's injunction); *Pennsylvania Ass'n for Retarded Children*, 343 F. Supp. at 305 (placing "the burden of going forward with the evidence" on the school district). These watershed cases not only served as the impetus for the Act, but outlined its eventual contours as well. *See* S. Rep. No. 94-168, at 6, *reprinted in* 1975 U.S.C.C.A.N. at 1430. The history of the IDEA thus demonstrates Congress's intent that "a State remains responsible for providing an appropriate education designed to meet the specific needs of the handicapped child at no cost to that child's parent." *Id.* at 10, 1975 U.S.C.C.A.N. at 1434. Since Congress sought to "incorporate[] the major principles of the right to education cases" through the Act, *id*. at 8, 1975 U.S.C.C.A.N. at 1432, it follows that placing the burden of proof on the schools is likewise more consistent with the Congressional intent behind that Act.

Third, placing the burden of proof on the schools is more consistent with the well-regarded policy of placing the burden of proof on the party with the "peculiar means of knowledge." *Alaska Dep't of Envtl. Conservation*, 540 U.S. at 494 n.17. This Court has routinely stated that "the ordinary rule, based on considerations of fairness, does not place the burden upon a litigant of establishing facts peculiarly within the knowledge of his adversary." *Campbell*, 365 U.S. at 96 (citing *United States v. New York, N.H. & H.R. Co.*, 355 U.S. 253, 256 n.5 (1957)). The IDEA explicitly recognizes that the school district, with its repeated experience in formulating IEPs, its recourse to the child-study team, and its access to experts and cumulative data, has special and particular knowledge and expertise needed to formulate an IEP. Early in the IEP process, detailed disclosure must be made by the district regarding the basis of its decisions, on the presumption that they hold the knowledge underlying the decisions that affect the child. *See* 34 C.F.R. § 300.503 (2004) (mandating detailed disclosure of explanations for IEP actions). And even though the IEP process is ideally an interactive and cooperative one with the parents, it nonetheless does not permit the parents to have access to school district information on certain issues of "teaching methodology, lesson plans, or coordination of service provision, … [nor] preparatory activities that public agency personnel engage in to develop a proposal or response to a parent proposal that will be discussed at a later meeting." 34 C.F.R. § 300.501(b)(2) (2004). The schools thus have exclusive access to the important information about historical ex-perience, while the parents may be left with, at best, an inchoate belief that a certain plan is not right for their child—and no opportunity to test that belief by comparison to the facts of prior experience, in the first instance. These exclusive activities of school personnel serve to underscore and enhance the relative superiority of the district throughout the IEP process.

Not only does the school have superior information and expertise; their representatives also dominate the IEP team. The regulations (34 C.F.R. § 300.344 (2004)) prescribe that the IEP team shall be made up of (at least) one regular education teacher of the child, one special education teacher of the child, a qualified and knowledgeable representative of the public agency, and an individual who is capable of interpreting "the instructional implications of evaluation results"—along with the parents of the child and a "parent representative." *Id.* § 300.344(a)(1)-(5). The parents are thus decisively outmanned by their "teammates"—not just in numbers, but in expertise, in training, in time, and in resources. One commentator describes the "team" thusly:

> The parents are outnumbered and surrounded at the big table by the professionals. Members of an ongoing team with its own internal dynamics, the professionals are more reluctant to oppose one another than to oppose the lone "outsider." Parents are inherently suspect because of their emotional attachment to the child, and [IEP team] members assume that parental preferences reflect subjective rather than objective judgments. Since more is at stake for them than for anyone else at the table, parents generally are anxious and inarticulate. They are often less educated than other [IEP team] members and are non-conversant in the technical language or concepts used during the meeting.

Engel, 1991 Duke L.J. at 193-94 (citing Singer & Butler, *The Education for All Handicapped Children Act: Schools as Agents of Social Reform,* 57 Harv. Educ. Rev. 125, 142 (1987)). Thus, because the school districts are comprised of educational experts, who are repeat players in the IEP process and who have access to a broad spectrum of information about other IEP plans that have worked (or not), it is especially appropriate to allocate the burden of proof to the school districts. *See, e.g., Alaska*, 540 U.S. at 494; *Concrete Pipe & Prods. of Cal. v. Construction Laborers Pension Trust,* 508 U.S. 602, 626 (1993).

Fourth, placing the burden on the school system leads to the efficient use of judicial time and resources by creating desirable incentives for school districts to articulate and communicate their educational practices. The IDEA admittedly grants significant deference to the educational preferences of school districts "on issues such as teaching methodology, lesson plans, or coordination of service provision." 34 C.F.R. § 300.501(b)(2) (2004). But the reason schools get this deference—their expertise—is itself a compelling reason for allocating the burden to the schools in the first instance. It will not be burdensome at all for these educational experts to come forward in the first instance with evidence and explanations for the IEP plan they have proposed. That regime would have several salutary benefits: For one, it will allow the parents to better sharpen the focus of their sides of the case by addressing the school's showings, in turn focusing and streamlining the hearing itself. *See O'Neal v. McAninch*, 513 U.S. 432, 436 (1995) (the burden of proof should be allocated in a way that "help[s] control the presentation of evidence at trial"). For another, allocating the burden to the school districts will "encourag[e] voluntary compliance by giving [the schools] incentives to self-report and to keep adequate records in case of dispute." *Raleigh v. Ill. Dep't of Revenue*, 530 U.S. 15 (2000) (placing the burden of proof on taxpayers in tax claims). It will also lessen the *in terrorem* effect that the adversarial IEP process works on the already-overwhelmed parents of children with handicaps, and empower parents to be better and fuller participants in their children's education.

Fifth, placing the burden of proof on the school districts in the due process hearings effectively "handicap[s] a disfavored contention" bearing on important public concerns. *See* 2 *McCormick on Evidence* § 337, at 413. Courts have employed this presumption when facing statutes that are enacted to achieve a particular public purpose, but silent as to burdens of proof in enforcing that purpose. For instance, in the *Regional Rail Reorganization Proceedings*, 421 F. Supp. 1061 (Special Court 1976), the court considered the viability of employee pension plans under the Regional Rail Revitalization and Regulatory Reform Act of 1976. Recognizing that the Act was enacted for the public purpose of "protecting all those employees and beneficiaries of the bankrupt railroads who were unlikely to be financially secure without pension aid," Judge Wisdom, writing for the Special Court, considered ConRail's position that certain plans were invalid as a "disfavored" position, and thus allocated the burden of proving invalidity on ConRail. *Id*. at 1073. An alternative holding, the court explained, would allow ConRail to protect itself, “where Congress obviously wanted [it to protect] the average worker or beneficiary. *Id*. So too here: Congress “obviously wanted” to protect disabled students (by ensuring them an “appropriate free public education”), and since school districts, if “[l]eft to [their] own devices,” will “choose the educational option that will help it balance its budget,” rather than the one best suited to the child’s individual needs, *Deal v. Hamilton County Bd. of Educ.*, 392 F.3d 840, 864-65 (6th Cir. 2004), the schools’ self-interest is appropriately “disfavored” by allotting the burden of proof to them, rather than to parents.

Sixth and finally, placing the burden of proof on the school districts in the due process hearing gives proper consideration to the realities facing parents of children with disabilities. Detailed in Section II, below, are many of the specific realities of daily life in the families of children with autism. Those burdens, coupled with a parent’s responsibilities under IDEA, are plenty: Under IDEA, parents are to be collaborative partners with the schools and an individualizing force behind structuring a child’s education program. *See, e.g.*, 34 C.F.R. §§ 300.501(a)(1), 300.501(a)(2), 300.504, 300.505 (2004). The job of the schools, however, is to actually provide that “appropriate” education program, so it is far more appropriate that the schools bear the burden of establishing the propriety of that program. The Court should not saddle the already-burdened parents of children with disabilities with the additional legal burden of proving that such a program is educationally inappropriate, especially when there are professional educators who will be repeat players, and who can better frame, focus, and carry such a burden at due process hearings. Otherwise, the parties who Congress intended to benefit from IDEA would instead find themselves only burdened, and appreciably so, by the operation of that statute.

II. THE SPECIAL CHALLENGES OF PARENTING A CHILD WITH AUTISM HELP TO DEMONSTRATE WHY SCHOOLS, NOT PARENTS, SHOULD BEAR THE BURDEN OF PROOF IN IEP DISPUTES

In the world of special education, parents are *the key* to child success. *See President's Commission*, at 38. Nowhere is this statement more true than in the case of parenting a child with autism.

"Autism" generally describes a developmental disorder which challenges a child's ability to communicate and interact socially. According to the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (4th ed. 2000) ("DSM-IV"), autism includes a wide spectrum of symptoms and degrees ranging from mild to severe. *Id.* at 70-71. But regardless of the severity of the condition, autism has three basic components: communication problems, gross and sustained impairment in social interactions, and unusually restricted and repetitive patterns in behavior, interests, and activities. *Id.* For example, a child with a profound autistic disorder may have great difficulty even communicating at a basic level, while a child with Asperger's Disorder, which falls within the autism spectrum, may have little difficulty communicating, but great difficulties in social interactions. As a result, "[t]here is no single best treatment package for all children with [autism]." *See* National Institute of Mental Health, National Institutes of Health, Brochure No. 04-5511, *Autism Spectrum Disorders (Pervasive Developmental Disorders)* (2004), at 8 (available at http://www.nimh.nih.gov/publicat/autism.cfm) (hereinafter "NIMH, *Autism Spectrum Disorders*").

Being a parent under any circumstance is difficult (if nonetheless rewarding). But parents of the children covered by IDEA have additional challenges. In the particular case of parents of children with autism, for example, the parents have to educate themselves about the condition itself, its various treatments, and its prognoses, just to adequately raise their children. This task is made more difficult by the fact that autism comes in many forms, and the precise type and severity of the autism disorder may not make itself fully known for years after onset of recognizable symptoms. *See* P.A. Filipek *et al.*, *Practice Parameter: Screening and Diagnosis of Autism, Report of the Quality Standards Subcomm. of the Am. Academy of Neurology and the Child Neurology Society*, 55 Neurology 468, 471 (2000).

Even with a certain diagnosis, the medical community does not speak with one voice with respect to the proper treatment of the condition: "It can be confusing and overwhelming to hear about all of the different treatments for children with [autism]. . . . [T]he history of treating children with [autism] also is riddled with eccentric, faddish, expensive care that is later shown to be needless or without merit." Kenneth E. Towbin, *Autism Spectrum Disorders*, in *When Your Child Has a Disability* (Mark L. Batshaw, M.D. ed., 2001), at 349. "Even the most experienced highly trained professionals can find it difficult to sort through the claims and evidence about treatments for autism. For families who may know nothing about autism at the moment someone applies the label to their young child, the task can seem overwhelming." Gina Greene, *Evaluating Claims About Treatments for Autism*, in *Behavioral Intervention for Young Children With Autism: A Manual for Parents and Professionals* 16-17 (C. Maurice ed., 1996). This only highlights the critical need for parents to educate themselves sufficiently in order to make considered and informed decisions about the course of their child's treatment and education. *See* Benedict Carey, *Autism Therapies Still a Mystery, But Parents Take Leap of Faith*, N.Y. Times, Dec. 27, 2004.

Still, when a child is first diagnosed as having autism, most parents "discover, to [their] surprise, just how scarce the resources are for parents … how thin the knowledge" is, and how varied the theories and guesses are as to autism's cause, components and treatment. Bob Wright, *I Want My Grandson Back*, The Today Show, Feb. 25, 2005 (available at http://www.msnbc.msn.com/id/7024923/). They may find it hard to comprehend that "a disorder with the frequency of autism commands so little public attention and such meager resources devoted to research, [certainly] compared to other, less common childhood disorders." *Id*. Research for childhood cancers, muscular dystrophy, juvenile diabetes, and cystic fibrosis—all of which combined together are less common than autism—is collectively funded to the tune of over $500 million annually, while autism research receives only $15 million per year from private sources. *See id.* It is thus unsurprising that parents of children with autism almost inevitably find themselves adding to their already awesome parental role by taking on the job of advocate—building awareness, raising funds for medical research, and advocating social and educational opportunities, among other things. *See* Robert Bazell, *Parents Push for Autism Cure; Doctors Credit Parents for Making Research a Priority*, MSNBC, Feb. 23, 2005 (available at http://www.msnbc.msn.com/id/7012176/).

With rare exceptions, no disability claims more parental time and energy than autism. Teaching a child with autism even the simplest tasks is highly time-and-effort intensive; managing the child's challenging behavior requires unflagging vigilance; and, perhaps most painfully, coping with an autistic child's seeming indifference to loving overtures can be discouraging to a committed parent. *See generally* Douglas Moes, *Parent Education and Parenting Stress*, in *Teaching Children With Autism* 80-81 (R. Koegel & L.K. Koegel eds., 1995). One of the few universally agreed-upon notions in treating autism, however, is that constant parental involvement is crucial to the success of the child. Towbin, *Autism Spectrum Disorders*, at 351 ("parents are the most important resource for learning about other people and for fostering social interactions. . . . [they] are crucial for implementing treatment programs and for being advocates for [their] child’s educational placement and other needs”); NIMH, *Autism Spectrum Disorders*, at 9 (“[p]arental involvement has emerged as a major factor in treatment success”).

A recent article by a *New York Times* writer about his son (a child with autism) illustrates many of these basic challenges. John O’Neil, *Slow-Motion Miracle: One Boy’s Journey Out of Autism’s Grasp*, N.Y. Times, Dec. 29, 2004. That boy, named James, appeared to be a “bubbling two-year old who loved ‘mashed totatoes’ and sword-fighting.” But that happy and engaged child was soon replaced by a “silent, unhappy child who repeated meaningless phrases, lay on the floor squinting or pulled cowboy boots on and off until his feet were raw.” *Id*. After James was diagnosed, his parents put together a “bedside library” of books and other resources on autism, so that they could be useful participants in James’ continuing development, education, and therapies. They learned that there *are* effective treatment options, but that those options are both cumbersome and expensive. The local school district willingly “prescribed” 10 hours per week of one-on-one therapy—but when James’ parents noted that several of their sources had recommended intensive, 40-hours-per-week autism therapy, the school district flatly insisted that “quality, not quantity,” was what mattered. *Id*.

In fact, autism research has recognized that, in the early years (ages 2-5), there exists a limited “window of opportunity” during which children with autism can effectively learn. *See* Gina Green, *Early Behavioral Intervention for Autism*, in *Behavioral Intervention for Young Children With Autism: A Manual for Parents and Professionals* 39 (C. Maurice ed., 1996) (“The optimal age to begin intensive behavioral intervention is before the age of 5. So far, the best outcomes have been reported for children who started treatment at age 2 or 3.”). Upon early diagnoses of the disorder, pediatricians commonly admonish parents to “immediately, immediately do something fast, now, right now” or risk “losing your child.” *Jaynes v. Newport News*

School Bd., 2000 U.S. Dist. LEXIS 21684, at *1, *19 (E.D. Va. Sept. 7, 2000). Courts have begun to issue the same admonishments. *See J.H. v. Henrico County School Bd.*, 326 F.3d 560, 569 (4th Cir. 2004) (ordering a hearing officer to consider "window of opportunity" evidence when considering summer services for autistic child); *Lawyer v. Chesterfield County Sch. Bd.*, No. 3:92CV760, 1 Early Childhood L. Policy Rep. 297 (E.D. Va. May 24, 1993) (requiring school district to provide intensive and uninterrupted therapy during that "window of opportunity").

The most common treatment program during this "window," Applied Behavior Analysis (ABA), calls for highly structured, one-on-one interaction between a teacher and a child for 20 to 40 hours a week. *See generally* Lynn M. Hamilton, *Facing Autism* 81, 83, 90 (2000). Because of the explosion in diagnosed cases of autism, there is a great demand for these services during the "window"; for the privileged few, private schools have begun to emerge to provide the necessary services. But both demand and cost is enormously high for these few private-school slots: Even if a family makes it through the often-lengthy waiting list before the "window of opportunity" closes, the cost of these private schools can reach up to $70,000 per year. Sue Herera, *Demand Soars For Autism-Related Schools, Services*, CNBC, Feb. 25, 2005 (available at http://www.msnbc.msn.com/id/7013436/). (By comparison, the median income for American households is just over $43,000 per year. Press Release, *Income Stable, Poverty Up, Numbers of Americans With and Without Health Insurance Rise, Census Bureau Reports*, U.S. Census Bureau CB04-144 (Aug. 26, 2004).) Parents unable to pay this hefty price may opt to employ an individual therapist for 25 hours per week at a price of roughly $5,000 per month ($60,000 per year) for their services. Sue Herera, *Parents of Autistic Kids Battle For Medical Coverage*, CNBC, Feb. 23, 2005 (available at http://www.msnbc.msn.com/id/7012824/). A bare-bones in-home program—one that is run by the parents with some minimal help from a consultant, and staffed by uncertified "therapists" (usually college students)—costs $20,000 to $25,000 per year, according to a nine-year-old resource. Stephen C. Luce & Kathleen Dyer, *Parents' Questions, Parents' Voices,* in *Behavioral Intervention for Young Children With Autism: A Manual for Parents and Professionals* 352 (C. Maurice ed., 1996). Most often, health insurers deny coverage for this therapy on the ground that it is "medically unnecessary"; that leaves the parents with the options provided by public schools, or in court to sue their insurance company for coverage. *See The Autism Epidemic—Is the NIH and CDC Response Adequate: Hearing Before the House Comm. on Government Reform,* 107th Cong. (Apr. 18, 2002) (testimony of Lee Grossman, President, The Autism Society of America) (noting the lack of insurance coverage for autism therapy, and that "[t]he only avenue … available to [parents] is services provided … by the educational system"); *cf. Auton v. Attorney General of British Columbia*, [2002] B.C.J. No. 2258, 2002 BC. C. LEXIS 4799 (B.C. Ct. App. Oct. 9, 2002) (holding that ABA therapy is a "medically necessary" service that must be funded by that government's health-care system).

Here in the United States, wide social gaps exist in taking advantage of the limited "window of opportunity." Studies show that while signs of autism are visible before a child turns two, white children enrolled in the government health insurance program Medicaid are generally diagnosed at an average age of 6.3 years. David S. Mandell, Sc.D. *et al., Race Differences in the Age at Diagnosis Among Medicaid-Eligible Children With Autism,* 41 J. Am. Acad. Child and Adolescent Psychiatry 1447 (Dec. 2002). Hispanic children are diagnosed at an average age of 7.4 years, and African-American children are diagnosed even later, at 7.9 years. *Id. See generally* Alison McCook, *Autism Diagnosis Comes Later For Blacks Than Whites*, Reuters, Nov. 13, 2002. And early diagnosis is only half the battle; only the strongest and most well-off of families can afford, financially as well as emotionally, to "fight the system" on all the necessary fronts, as well as put in place stopgap measures pending the resolution of the legal and educational fights. When school districts refuse to provide the necessary intensive therapy during this important period, precious few parents have the resources to pay for private instruction or to battle an insurance company.

Thus, for most families, the IDEA-guaranteed "free appropriate public education" is the only option. Unfortunately, so many of these parents still find themselves "hir[ing] a lawyer before they meet the preschool teacher." Jane Weaver, *Inside the Treatment Maze—No Single Approach is Best for Every Child*, MSNBC, Feb. 23, 2005 (available at http://www.msnbc.msn.com/id/6948119/). It goes without saying that this only diverts the parents' finite time, energy, and finances from educating and rehabilitating the child during the formative and fleeting "window of opportunity." *See President's Commission*, at 40; *see also School Comm. of Burlington v. Dep't of Educ.*, 471 U.S. 359, 370 (1985) (noting that parents without "adequate means" are left to engage the "ponderous" review process of IDEA and, in the meantime, "go along with the IEP to the detriment of their child").

James, the boy described in John O'Neil's *New York Times* article, was fortunate enough to have parents who could provide both a temporary private education and a long-term legal strategy: They were strong-willed and otherwise sufficiently equipped to recognize that "if [they] let the district pound on [their] child without hitting back, the pounding would never stop." *See* O'Neil, *supra*. So they hit back: The parents first sued the school district for not providing James an appropriate education. His mother then gave up her full-time job; his parents remodeled their basement; and they employed an autism expert to establish a specialized "school for one." But their investment paid dividends: The tedious, intensive therapy eventually "jump-started some slumbering connection in [James'] brain."

Seemingly tiny steps such as touching his nose on command, asking for "cheese crackers," and rolling toy cars down steps were giant leaps for young James. After a year of therapy, James began "waking up," but the drain of "time, emotion and money" was exhausting on James' family. *See* O'Neil, *supra*.

In fact, the personal costs of dealing with raising a child with autism may be even more dear than the out-of-pocket costs. A British study found that parents there caring for a disabled child often reported severe depression leading to, in some cases, nervous breakdowns. M. Dowling & L. Dolan, *Families with Children with Disabilities—Inequalities and the Social Model*, 16(1) Disability & Society 21, 30 (2001). Children with autism present particular challenges with respect to parental depression, because such children are often incapable of showing and reciprocating love in the typical and expected ways. *See* Stanley I. Greenspan, M.D., *The Affect Diathesis Hypothesis: The Role of Emotions in the Core Deficit in Autism and in the Development of Intelligence and Social Skills*, 5(1) J. of Developmental and Learning Disorders 1, 5 (2001). The behaviors characteristic of children with autism can lead to the entire family's "exclusion from mainstream and integrated school and community environments." D. Moes, *supra*, at 84 (citing research studies). With vast financial resources and parents' finite time being devoted to the upbringing and education of the child with autism, "the whole family unit" can and often does become strained. Dowling & Dolan, *supra*, at 24. Other children in the family without autism may begin to resent the disproportionate attention being paid to their sibling with autism, *see* Jane Gross, *For Siblings of the Autistic, A Burdened Youth*, N.Y. Times, Dec. 10, 2004, and the inevitable re-centering of the parents' attention on the child with autism can cause the marriage itself to wither and die from neglect. *See generally* Towbin, *Autism Spectrum Disorders*, at 352. Recent Congressional remarks note the extraordinarily high divorce rate of affected families, *see* 150

Cong. Rec. H2596 (daily ed. May 5, 2004) (statement of Rep. Murphy), and therapists are now beginning to see a spate of cases where parents commit suicide because they are unable to deal with the toll of the disorder. *See* Victoria Clayton, *Coping with Autism; Families Connect and Deal with the Diagnosis*, MSNBC, Feb. 24, 2005 (available at http://www.msnbc.msn.com/id/698852/).

The system intended to defray these high costs is far from perfect: Parents are forced to fight for their disabled child's rights, often at the expense of the relationships that are intended to facilitate education and a functioning family unit. Engel, 1991 Duke L.J. at 194-205. And despite such committed advocacy, at present, "only a relative handful of children with autism are thought to receive even the minimum standard of care, a pattern reflected in an increase in requests for institutional placements as the leading edge of [the] last decade's [children with autism has begun to] reach[] adolescence." *See* O'Neil, *supra*.

A recent study in the United Kingdom confirmed that adults with autism, even "high-functioning" individuals, have tremendous difficulty in living independent lives, and that parents of such individuals shoulder the burden of caring for them well beyond their school years. *See* The National Autistic Society, *Ignored or Ineligible? The Reality for Adults with Autistic Spectrum Disorders* 6-7 (2001) (reporting that "70% of parents felt that their son or daughter would be unable to live independently without support[,] [l]ess than 10% of adults can manage the most basic household tasks such as shopping, preparing meals, laundry, paying bills, managing money, without help," and "only 3% of adults at the higher end of the autism spectrum are living fully independently, and a further 8% are living independently with some regular professional or family support"). For the parents of a newly diagnosed three-year-old with autism, the real issue becomes whether that child's college fund will instead be available as a "group home fund."

The societal costs of institutionalizing young adults far exceed any costs that might be incurred at the elementary and pre-elementary levels. *See* J.W. Jacobson *et al.*, "*Cost-Benefit Estimates for Early Intensive Behavioral Intervention for Young Children with Autism*," 13 Behavioral Interventions 201 (1998) (estimating societal savings over the life of a person with autism of between $1.6 and $2.8 million per person with autism if intervention is widespread, early and effective). If one of the goals of education is to prepare as many children as possible to become society's productive and integrated adults, it cannot possibly be considered a success if the "free appropriate public education" guaranteed by IDEA ends up with more young adults in public institutions for the rest of their lives.

* * * *

This Court cannot make autism go away. It cannot give parents the seemingly infinite inner strength and financial resources needed to raise a child with autism. Nor can it guarantee that families and marriages will not be crushed by the weight of the burden of raising a child with this condition. But what it can do in this case is to recognize the policies of the IDEA, and the realities of raising a child with special needs (of which autism is only one recurrent kind), by placing the burden of proof in IDEA cases on the school district, where it appropriately lies. The end result will be that educators will have the burden in matters of education, and parents will have the burden in matters of parenting. That is completely consistent with the goal of the IDEA to provide a free appropriate public education; it is completely consistent with the respective responsibilities of the IEP "teammates"; and it is a completely sensible, and eminently workable, result.

CONCLUSION

For these reasons, *amici* urge the Court to reverse the judgment of the Fourth Circuit.

Respectfully submitted,

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