

**Case Preparation,
& Disabilities and Human Rights
E-Interview with Ilise Feitshans, JD**

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By Janie Bowman

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Describe the significance of the ruling in *Florence County School District v. Shannon Carter* (decided November 9, 1993). Was this ruling instrumental in empowering parents to be more proactive legally?

Yes, it was a wonderful case in its time. Unfortunately, it is “honored in the breach” under law. In other words, people have lost sight of the principles that were the driver of that case. We need a national agenda that will crystallize new views of disability, reaching all types of disabilities, understanding the little bits of disability that exist in everyone, exploring the good things accomplished by “healthy disabled” people, and celebrating the gifts of all people.

***Winkelman v. Parma City* is currently before the U.S. Supreme Court. Please briefly explain the specifics of this case and how, in your opinion, it will impact families who bring IDEA claims on behalf of their children with special needs.**

This case is a sad comment on the current law. The parents must win this case, in order to retain the right to go to court. That is a shallow right—few people would deliberately go to court without a lawyer unless, not only haven’t they any money, but there are no legal experts willing to take the case. Such parents have rights, but will not win anything. Next month, the U.S. Supreme Court will hear its third special education case in two years. This case will touch the lives of every child in school in the USA, in public or private settings, because inclusion under this statute requires

that students with identified disabilities have the right to go to school with students who have no identified disabilities at all. So there is not a classroom in America where this case will not apply. Therefore it impacts the rights of every parent who has a child in school, and it impacts the implementation of those rights in daily life.

This case is an example of the U.S. Supreme Court as everyone's court, involved in the issues that face real people all the time. If the Court decides wisely and its decision is applied prudently, it can become a shining moment in our law, a time when the law at its best helps all of society.

Regarding the specifics of this case, of the ten thousand cases submitted annually to the U.S. Supreme Court requesting “certiorari” (to be heard) only 80 (eighty) go to oral arguments. Additionally, the significance of this case as a precedent is huge in light of the 2005-2006 precedents discussed below: *Schaeffer v. Weast*, and *Arlington v. Murphy*. *Winkelman* provides an opportunity for the U.S. Supreme Court to trim back two decisions that went too far — went further than is politically tenable in the USA.

Even if one accepts the proposition that people in the USA are unaware of their rights to special education until someone in their family actually needs them, and that there is a popular myth that special education costs a lot of money, which it does not, when done properly--- even so, the devastation of the right to special education that follows from last term’s decisions must be corrected. For one thing, the Individual Education Plan (IEP) established under the statute in question is, by the terms of the law, a contract. If the parents do not have the right to enforce the rights of the IEP as a contract on behalf of their child, what right do they have to participate in that contract at all? At its logical extreme, the notion of depriving the right to go to court for parents who are competent, acting in unison to enforce specific statutory rights flies in the face of our entire history of parental discretion insofar as educational decisions about one’s own children are concerned. This case becomes important in light of the fallout from the case of *Schaeffer v. Weast*, which went too far, and is also being applied inappropriately in school districts across the USA.

I am surprised that the issue has come up at all; taking together the language within the statute that ensures parent involvement in decision making along with the long-standing USA tradition of parental discretion regarding all types of decisions about education makes it unlikely that a parent could not represent their child, *pro se*, in matters of education. The sole exception would be if there were a problem with the parent’s competence, such as disability in the parent or some other limitation. Ever since World War I, when the U.S. Supreme Court upheld the rights of parents to have their children learn German even though we were at war with Germany, no one has

ever seriously challenged a parental right to make education decisions for a child. Indeed, private school vouchers for religious education would make no sense at all under law if the existence of some inchoate parental right of decision making about education were not true. In the light of two previous cases from the 2005-2006 term [Schaeffer v. Weast (Nov 2005) and Arlington v. Murphy (June 2006)] this case takes on greater importance for ensuring student rights and the ability of parents to make decisions about the education of their own child.

Schaeffer in particular is very unfortunate, because its decision that the party bringing the claim in due process bears the full burden of proof has two very destructive effects. First, we have absolutely gutted the accountability for school districts that was built into the IDEA. If parents bear the burden of proof, how can they ever persuade a court or an administrative law judge that they have greater expertise? They cannot. That is not why the statute was written the way it was. The school bears a burden of accountability that was inadequately briefed by the family's counsel in Schaeffer. So when the U.S. Supreme Court asked, in effect, "What makes you any different from any other plaintiff who wants a low burden of proof?" there was no right answer. The question to have asked really was, "If we treat the parents and the school district as equally endowed with expertise and the ability to produce reports and qualitative information about special education, why would we need any experts to report at all—we simply could accept the words of the school district experts without further question and end all accountability or scrutiny of school district decision."

I do not believe that it was genuinely possible for the Schaeffer facts to be in "equipoise" because of this inherent difference in the ability to muster evidence, the statutory mandate to provide accountability and a check on school district decision making, compared to the ability of parents to evaluate situations and pay for experts. Nor should parents be expected to do so — indeed, why do we have school districts if parents can do that by themselves?

Second, the effect in practice is that school districts don't even bother to attend some due process hearings, and avoid it by simply submitting paperwork in evidence. They also use a variety of tactics to provoke the parent into going into court first when there is a dispute, thus relishing the new advantage they hold regarding the burden of proof. Poof, no proof-- no accountability-- no further questions-- unbridled discretion in the school district's hands. In sum, Schaeffer is just a disaster for the future of all education, not just special education, because of its failure to provide appropriate oversight. The failure also to correctly exercise the statutory principles of inclusion harms all students—not just special education, but the so-called mainstream or "regular" education students who need to learn to live with people who possess a variety of disabilities. Everyone has a disability at sometime in their life, everyone has

a gift. Learning to cope with disability is a life skill that schools must teach to their students, regardless whether they have been identified with a disability when they move through the portals of education as they journey through schooling.

Arlington v. Murphy simply sealed closed the coffin on questions of burden of proof, by denying the parents certain types of expert fees. It is really difficult to bear a burden of proof in the first place, but now parents must pay for the expertise that they use. So much for the notion of a “Free Appropriate Public Education.” People who pay thousands of dollars a year for public education because they must hire experts to rebut any inadequacies in the existing system are simply not getting education for free. We all suffer when the system is broken, because we all need every citizen to be well educated, to become employable taxpayers and then contribute their gifts to society.

So now in *Winkelman*, the U.S. Supreme Court must re-affirm the long-standing right of parents to make educational decisions for their children, which is reflected throughout the so-called “partnership” of parental involvement in the statutory scheme of IDEIA and is also reflected consistently for centuries in our social fabric—ranging from the choice whether to select public or private schools or to engage in secular or religious education. These notions have been sacred throughout USA case law, and it would be impossible to protect these very dear fundamental tenets if parents lose all their rights just by having a child who needs special education. Ironically too, many religious private schools do a great job of special education, and depriving parents of the full panoply of their rights to make choices by standing as pro se for their minor child would inevitably deprive them of the opportunity to enjoy those educational opportunities.

Given the impact of the last two rulings (see comments above), how can parents be assured their IEPs are bulletproof?

There are no fireproof buildings and there are no bulletproof IEPs. If a school wants to help the student, in theory they don't even need to write it down if there is a commitment to good education. If they have no intention of following the IEP, there is no amount of paper and writing in the world that will ensure in advance that they will do their job. And, in truth, the administration and staff will get their paycheck either way-- whether they help or hurt. The two previous cases just made it harder to make the school districts accountable. *Schaeffer* basically stands for the proposition that who goes to court first bears the burden of proof. That is contrary to some of the language of the statute, but it also means that a school district can stonewall until a parent who never in their life expected to litigate against a public school either pays for private schooling or takes the school district to court (or both). In that case, the

Schaeffer decision, if followed, would make the parent bear the burden of proof even though the school district has experts, a huge budget and a statutory mission to provide accountability for its determinations. And, under Murphy, the parent must pay for their own expert fees. So now the school districts basically can't lose, unless a parent has unlimited funds. In that circumstance, why would the parent keep the child in public school instead of purchasing a great private education? One must hold dear the litigant who comes to court with unlimited resources in order to fight for a principle such as Free and Appropriate Public Education (FAPE) under law for students who need special education.

What's involved in case preparation, and what's important for parents and advocates to include in case preparation?

I think the hardest thing about a case is to start. Feeling a sense of unfairness in special education, that's easy. Telling your friends that there is a problem is a little harder, but it is inevitable that problems will eventually out themselves in front of friends—a child misbehaves, a teacher doesn't understand, a spouse or ex-spouse fails to attend an IEP meeting and suddenly the entire story pours out of one's heart before friends. That's harder but still easy. Feeling the sense of unfairness is so great that it rises to the point of injustice, and that such injustice can and must be addressed using a complex apparatus embedded in the law — that is more difficult.

Understanding that there is law to guide the parameters of the special education situation and that some part of that injustice is illegal is very complex. And once that realization occurs, one must crystallize all that pain from the injustice into a well-crafted complaint that is rather devoid of emotion and addresses only that which is illegal, which may be very different from the actual harm experienced by the child in a classroom. And then, last but surely not least, mustering the courage to take that clear sense of illegal injustice, put it into a few crisp sentences and send that complaint off to powerful strangers who may or may not read the document and if they read it may not care, that last step is very difficult to do unafraid.

But the law is not the woman's world of oral communication and resolution by talking things through. The law is a man's world of literate documentation—probably the most unfair feature of special education, where many of the protected constituents will not be able to understand or use written tools with the mastery required to win a litigation under law, and certainly will not be accessible to children who have not yet attended college or law school.

Ironically, the first step is this difficult creation of paper trail and where it will lead may end up in the U.S. Supreme Court as we have seen in three recent cases— Schaffer v. Weast in Nov 2005, Arlington v. Murphy in 2006 and Winkelman v. Parma City in 2007.

Case preparation takes a lot of time and money. Document everything. Don't use email. Fax a letter instead. Fax anything you want to say on the telephone. First write the letter and then put it in a drawer for a day. Not more than 24 hours, because complaints must be timely. But put it away, and then come back to it. Check for grammar and spelling and content. Then fax it to the head of the Child Study Team or the Office of The Superintendent, or state officials. Do not telephone. Phone tag is an economically inefficient waiting game; an invitation to be put on hold with no record even of your call, much less what you thought you said or whatever concessions you might believe were verbally agreed upon.

What's the average time it takes a case to go from mediation to the U.S. Supreme Court? Do you know the approximate costs to parents and school districts to pursue the issue to this point?

YEARS. The cost is very high. These cases are very aggravating. The pressures and the emotional cost and the economics of these cases can break up marriages and they destroy family budgets, but there is no choice — the cases must be fought because the alternative is to have a child whose future is reduced to oblivion.

In your opinion, what is the most important thing to remember while advocating for children with special needs?

The system is BROKEN. Nobody cares about your child except you, yet you must find ways to create coalitions with other parents, with teachers and with staff. It is crucial to find allies for small bits of the problems, but there are no quick fixes and no massive overhauls of the system that will get it right. It is disillusioning to realize that public education, which was more than adequate for my father, a lawyer, my mom, my grandparents and my great-grandparents, does not work anymore. Public education made this country great, but we have lost our commitment to it and that is most obvious in special education. Special Ed students are simply the canaries in the mines — the most sensitive to the dangers and harms — but that does not change the reality that the harms threaten the education of everyone.

Thank you for your work in the area of disabilities and human rights. As a society, what can we do to address the needs of people with disabilities while also benefiting people worldwide?

I think it is really the same to benefit people with disabilities and benefit everybody. Everybody has a disability, and everybody has a gift. Furthermore, even if you were to find the perfect person, I defy you to find a perfect family.

A family is a collection of imperfect people, many of whom spend a great deal of time covering for each other, either through direct means, such as deliberately employing compensatory strategies for disability; or by denial, as in a comfortable friend who is also a false friend because, in the end, disability will out itself. Therefore, one must know one's limits in order to master them.

So even the perfect person would need to cope with disability in their own family, at school, in a colleague at work, or in someone not related by blood whom they love or encounter by happenstance. Disability is a paradoxically common part of the human condition, even though it manifests differently in each person.

As I said in my writings and comments prepared for the Columbia University Seminars on Human Rights¹ (Nov 1, 2006), "Disability is a universal and pervasive facet of the human condition." No two people will experience it equally. Universality is a fundamental cornerstone of human rights norms. So disability protections, including the freedom from prejudice, would seem natural if not positively codified under human rights norms. But, this is not the case.

Paradoxically, disability presents the inherent challenge of understanding, accepting, and allowing society to benefit from the most individualized of individual experiences: difference. Disability, although universal in its likely incidents, also challenges the operationalization of a fundamental tenet of equality: that every person is the same. Everyone is different yet everyone must have the opportunity to be treated the same. This is important when we think about rights.

¹ Feitshans, Ilise. Diversity and Human Rights: Protections for Neurodiversity and Physical Disabilities Under International Human Rights Law. Paper prepared for the Study of Human Rights, Columbia University Seminar "Diversity and Human Rights." Nov 1, 2006, in New York, New York. <http://www.columbia.edu/cu/seminars/pdf-files/adding.pdf>.

What are rights? According to Hohfeld, as quoted by Shue,² “Rights are not merely gifts or favors motivated by love or pity for which gratitude is the sole fitting response. A right is something that can be demanded without embarrassment or shame”.

Few areas of human existence demonstrate this point as easily as protecting people with disabilities. When we think of disability, healthcare and Medicare immediately leap to mind. Issues such as privacy, autonomy, and the respect for the freedom of speech — these are central to the protections discussed in the United Nations Draft Protocol and disability literature. Thus, disability actually transcends both realms and does so more convincingly than other sources of equality in international human rights. Existing international human rights laws can be applied to implement the protections of people with disabilities including the Draft Protocol, which provides an excellent catalogue of rights although it may be too cumbersome to be practical.

In my paper, I argue there is no shortage of international law for people with disabilities for two reasons: First, the protections between civil rights on the one hand and economic and social rights on the other are discussed in the two international covenants. Second, the notion that disability pertains to segmented portions of society that can be apportioned through something called diversity bespeaks a fundamental misunderstanding of disability itself. Every individual in society will recuperate or gain health or lose health at times in their lifetime. So, the population to be considered disabled will change across time even for people with long term conditions that are disabling, and no person lives an entire lifetime devoid of illness, infirmity, or physical disability whether it is an issue of a quality of life, genetics, accidents of nature, daily modern life, or war.

So, my paper *challenges the notion that disability is represented through diversity* despite the vital and important perspective that people who are working through their disability bring to the discourse. The real challenge for international human rights is to explain disability as a source of universality.

Everyone is different but everyone is the same. There is a fundamental tension in this paradox. No two people have precisely the same DNA or life path following personal decisions. Yet, everyone has basic human needs. The entire legal apparatus of our social protections for civil rights and liberties are predicated on this notion that

² Shue, Henry. 1980. *BASIC RIGHTS: Subsistence, Affluence and US Foreign Policy*. Princeton: Princeton University Press. Citing Feinberg, who was citing Wesley Hohfeld, *FUNDAMENTAL LEGAL CONCEPTIONS*. New Haven, Yale University Press 1923.

individual differences and universal components of the human condition are not mutually exclusive.

Does the difficulty of addressing these needs reflect a question of money, power, or both?

No. The issue is PREJUDICE. Everyone has a disability and everyone has a gift.

We must be candid and not jealous, and not mean or cruel, nor wishing to act superior to our colleagues. We must be intellectually honest with ourselves about our own limits and our own special needs.

We must be glad to find the unique gifts in others and willing to seek out and cultivate that gift no matter how unusual or unlike our own gifts. Or how much we wish we could do the same things. Or how much work it is to compensate for the things that the next person simply cannot do and will never be able to do.

Even though there are issues about empowerment among people as they interact, even though class matters increasingly in our society, the issue is neither power nor money.

The real issue is prejudice—the fear that we will somehow become disabled if we embrace people with disabilities or that they are going to do something strange. Sure they will, but guess what, I know plenty of people who are puttering around in our society who can be just as hurtful or damaging to the people around them yet they bear no recognized label of identified disability. People are who they are and we must accept them accordingly. And love them dearly, despite their disability.

Does advocacy on a local level translate to positive changes on a worldwide scope?

YES. Absolutely. Every bit of progress diminishes the lack of tolerance and the lack of understanding in an inextricably interdependent world.

How can advocates bridge the cross-cultural divide to advance understanding and actually gain real ground in helping others?

I think the hardest lesson is that disability, although different in each individual, is universal. I believe that if the international community could embrace this reality, that everyone has a disability and everyone has a gift, indeed we could accept the universality of disability and then work our social policies and coalitions from there.

Instead, the disability community itself—to the extent there is one—is balkanized Are people disabled enough for one political group or another? Are they “too disabled” to participate and gain acceptance elsewhere? And we have completely overlooked time and again the concept of the healthy disabled—people who live so much longer than was predicted by the survival curve when they were first diagnosed that no one knows how to predict their future outcome. These people may be in better physical shape, may have better heart health or better self-esteem and be more stable than people who are categorized as “normal”—whatever that may be — but they may suffer from stigma due to their disability.

If you had only one thing to say to parents and advocates, what would it be?

Never lose faith in your own child. If you think your child can do something and the administration claims that is impossible, your job is to find someone who will provide that opportunity to your child.

Children, unlike cars, toasters and a variety of household appliances, are not born with owner’s manuals for their parents. And, I sort of dread the notion of a society that might provide one. Nonetheless, it is good to have sound advice from talented and caring professionals. Finding such advice takes a lot of time and is very expensive.

Most important of all, don’t be selfish. Fight for the rights of others besides your own child. Fight at their side, even when they are unkind or uncertain allies. Because no matter what rights you get protected for your own child, those rights can be meaningless once they cross the threshold of the classroom or school house door, in a world that is fraught with destructive myths and prejudice.

Employability of this generation is the next issue after education. We have young ladies and young men who were cheated by this system, whose parents gave into stigma and denial and refused to aggressively seek timely redress against the school’s failure to address special needs—parents who failed to ask for enough help out of fear of the system or fear of what their neighbor’s would say about them. And those children do not succeed. Those children grow up to become more dependent, less able to function in society. Those children grow up needing social security disability in their twenties or earlier, never having a prospect of a stable wage in a rewarding job or a full life.

This is the most wasteful aspect of our broken special education system, because it is a hidden cost, and because the education system and the departments of labor and the people who run health systems within their employment do not communicate unless a parent, or a person with disabilities pressures the system by becoming their

own advocate. And, at that moment when the individual must assert their own rights, it is useless in an environment that is not receptive to the claims of the advocate.

That is why I urge parents to understand that although we are all different, there is universality in disability as a basic human need for understanding, accommodation and respect for our individual variability. Respect for our differences means having not just tolerance, but also a willingness to ferret out the gift in each person. Everybody has a disability and everybody has a gift. Our job is to understand that not only is there difference, but also an interdependent societal need to explore and benefit from the contribution of each individual using to the utmost potential their individual gift.

So, I say to parents, sure fight for your rights and for your child's special needs, unafraid of retaliation and unafraid of the social stigma that may follow from disclosure of your child's special needs. But fight also for the rights of others, because your child needs a world that is free of stigma, which can only come from a world that understands the unique needs and gifts in each person as a universal facet of individual human rights.

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