

"Dear Teacher: Are We Talking About the Same Kid?"

[Note: On March 6, 1998, LI TSA co-sponsored a conference for educators. During the morning plenary session, we arranged to have some speakers who spoke as professionals and some speakers who spoke from personal experience. As conference co-chair, I knew that somehow, educators needed to hear what we are living with as parents and needed to hear our concerns. And so I set myself the challenge of trying to give voice to what so many of us are living with. The following is a transcript of my talk. -- L.P.]

What is it that guy with the bad hairpiece says on TV, "I'm not only the club president, but I'm also a client?" Well, I'm going to step out of my role as a psychologist and chapter head and talk to you with my most important hat on -- as a mother. It would actually be a lot easier and emotionally safer for me to talk to you just as a psychologist or as an advocate than to try give voice to what some of us are living with or what we go through with the schools. Because I'm not going to be talking about the situations when things are going well between home and school, but only trying to explain the parent's take on why they sometimes go wrong. This afternoon, Irene Witthoft will be presenting a workshop on how to foster collaboration between parents and school. As the principal of the Captree Program, Irene has done an outstanding job of developing parental trust and support, and if you're struggling with parents, I'd encourage you to take that workshop.

There's just one thing I should mention before I get into what it's like to try to parent some of these kids and how many of us feel about our interactions with the schools. In a little while, you'll have the pleasure of hearing Sue Conners speak. As an adult who has TS herself, Sue has developed a terrific sense of humor about some of this stuff, and keeping a sense of humor when you're parenting or teaching a child who has TS is a real survival skill. And teaching the child to maintain a sense of humor can be really helpful. So I talk with Sue or I listen to Sue and I laugh. And I laugh with my husband and we have tried to help our children find the humor in situations. In my case, I'm the only person in my household who doesn't have TS or OCD. My husband has TS-ADHD-OCD, my son has the trifecta, my daughter has TS-OCD-anxiety spectrum disorders, And I've got my mother-in-law, Mrs. OCD herself, living with us. Are you getting the picture? And to make my life even more complete, I have a hyperactive dog and an oppositional cockatiel. So any way I can find to laugh about this all, I'll laugh. And sometimes, it's not hard to laugh because there are times that really are funny.

But there are some things that no one can laugh about or times where it's almost impossible to find any humor. So when you listen to Sue and myself or others laughing about some of this stuff, please realize that while adults have learned to laugh at times and some kids are learning to laugh at times, a lot of kids and a lot of parents can find nothing to laugh about. And even those of us who laugh publicly often cry privately.

In any event, I finally decided that one way to approach the conflict that sometimes occurs between the schools and parents is to pose the question, "Are we talking about the same kid?" because over and over again, I'm struck by how differently our children appear to us than to their teachers.

My son is almost 16, but I still remember his first day of kindergarten. At the time, I already had some suspicions that he might have TS, and had talked to the principal and his teacher before he

ever enrolled in the school because I was concerned and we were hearing things from his nursery school teachers that didn't bode well -- like that he kept throwing things up in the air. And of course, when those things came down, they occasionally hit other children. So there it was... his first day of kindergarten, and after school that day, I got a phone call from his teacher. She told me how my son had shoved a little girl in his class. Shoved a little girl? My son? Impossible. My son isn't aggressive. I asked her if it was possible that he had just bumped into or tripped into the little girl, as he tended to be a bit clumsy. But the teacher was quite clear that he had intentionally shoved her -- hard. I felt like I was entering a Twilight Zone. Finally, after a few minutes of asking her to describe exactly what she had observed, I said to her, "Mrs. Moskowitz, can you please physically describe the child you're talking about? What was this child wearing? Are we talking about the same kid?" Well, describe him she did....

That experience stayed with me, and was to be repeated many, many times over the years. I'd hear reports of how my son had behaved or things he'd said, and I'd shake my head and wonder whether I could trust the teachers' reports -- after all, what they were describing was so very different than how I knew my child to be. And in retrospect, I'm sure that there must have been times when the teachers wondered what kind of mother I was if my child could act that way. But I think I've been luckier than many other parents in that respect. Maybe because I have a professional degree, I didn't have to contend with a lot of educators suspecting that maybe I was responsible for my son's problems or that maybe the home environment was the problem. Other parents haven't been so fortunate. When I go out to schools to talk to educators, I know that there will always be at least one person there who will secretly harbor suspicions that the child's problems have nothing to do with TS and are solely the result of faulty parenting or having an overanxious parent or a parent who doesn't discipline enough, etc. etc. And I wish I had a dollar for every time some teacher or educator has suggested that the child doesn't even have TS because they don't see any tics in the classroom.

We need you to understand these kids better, and your being here today is a good start. We know we are not perfect, but no, what you are seeing is not the result of lack of trying on our part. And it's not that our kids don't know right from wrong or don't know how they're expected to behave. It's just that they are dysregulated and haven't yet learned to manage their dysregulation. They need our acceptance and support. They need your acceptance and support. And we as parents need your support and not your suspicion or disbelief. You want to know what it's like for some of us? Well in addition to dealing with the guilt that some of us feel that we passed on a disorder to our child that is causing them pain and suffering, or in addition to the grief that we may feel as we feel the loss of our perfect child, here's what it can be like if you're parenting a child who has TS+:

- Many of us have wiped out our savings on psychiatrists and psychotherapy because psychiatrist bills and psychotherapy are not really covered well by our insurance plans -- but we'd gladly forego vacations and new cars if it means helping our children cope with TS+ and learning how to support them.
- Many of us have developed defensiveness from having been disbelieved by our child's doctors and professionals. Some parents spend years taking their child to the doctor and voicing their observations and concerns, only to be told not to worry and that their child will outgrow this -- or that the doctor doesn't see anything wrong. We have lots of mothers who have spent years trying to get help for their child, but everywhere they turn, their concerns are invalidated and it is suggested that they are just overanxious moms.
- Many parents have taken the advice of professionals who have developed behavior modification plans, and when the plans don't succeed, they've been told, "Maybe you're not doing it right." So they have tried and tried again -- often to little or no avail. And we may get to feeling that no matter what we do, no matter how hard we try, it is somehow

our fault if our child can't control their symptoms. And that feeling only leads to more problems. And so when some of us approach the schools, we do with a history of not having been believed and no longer feeling competent as parents. And all too often, the schools don't believe us either, and contribute to the sense of making parents feel incompetent instead of recognizing that the parent may be doing everything right but that this is just the nature of the beast we call TS+.

- Many of us have given up jobs and income that we desperately need to stay home and take care of children who cannot function independently. And that financial stress only adds to the stress in the household.
- Many of us spend months on end when we're afraid to leave the house because the school might call to tell us that our child has fallen apart and isn't coping and needs to be taken home or that our child has acted out and must be taken home. A lot of parents land up getting beepers just so that they can leave their home.
- Many of us are estranged from our families who also don't understand what we're living with because they don't see it -- for the same reasons that you often don't see it -- because the child is different in different settings. So the grandparents who give the child one-on-one attention don't see what the school sees or what the parents see, and when the parent tries to talk to their own parent about their problems, they hear, "Well you're just not being strict enough... or you're being too strict." Some of us stop talking to our own families because they, too, become a source of invalidation... and some of us dread family get-togethers because under the conditions of excitement and stress, we know that we're going to have watch our child to make sure that they don't do something inappropriate. And frankly, how can we enjoy ourselves when the whole time we're trying to listen to Aunt Sadie's story, we're keeping a worried ear out for sounds of problems with our child? Most of us would rather stay home.
- Many of us are estranged from our friends, who also can't fully imagine what it's like to live in a household that gets stood on its head because of the child's symptoms or medication problems. We turn to other parents in TSA who will understand and who won't look at us with suspicion as if we had done something to cause these problems.
- And many of us pray to hell that our child's teacher will understand that our children don't want to be doing these things and that telling them to stop or punishing them just isn't going to help and may only going to make things worse for them -- if not in the school, then in the home. And if you make things worse for them, you make things worse for the entire family.

So... there *you* are, in the school, hoping for the parents to support your efforts, and there we are, needing your support. We write you notes, we bring you literature and videos, and we try to get you to understand that sometimes, the structure of your class or of your school program or the stress of trying to function in school is creating problems for our child. And we see our children getting worse in the home, and feel a sense of urgency to change the school situation to get some of the stress on the child down. And what do we hear?

- Maybe we hear, "Well we don't see a serious problem." And we're thinking, "Of course you don't. He's managing to hold a lot of it in until he gets home. What you're seeing is only the tip of the iceberg. You know all those tics you say you don't see in school? Well, you should see him explode in tics the minute he comes home -- it takes an hour for him to stop really ticking or crying or being angry." "You know that girl who you say is doing so well in school and isn't a behavior problem? Well do you know that she comes home and cries for hours and talks about killing herself because she's so miserable about how she feels in school?"

- Maybe we hear "your son is disrupting the whole class and while I know he can't help it and I feel badly for him, we can't tolerate that." And we think, "Well, what do you want us to *do*? My child doesn't want to be having vocal tics or jerking or twitching or compulsively doing things. Do you think that even when he acts like the class clown or acts defiant or like he doesn't care that he doesn't realize that he's not in control of himself? He knows, and he may not show it to you, but it's ripping him apart. And don't you know that if we could change things, we would?"

Sue Conners and I were talking the other night, and I suggested to her that someday, she and I sit down with her staying in the teacher role and me in the parent role and write up things that teachers say and how they're often interpreted by the parents. Because in all fairness, you might mean something neutrally and yet the parent will feel that there is an implied criticism or suspicion because many of us have spent years not being believed about our own children.

So each day, some of us live with a small knot in our stomachs, never knowing what kind of note or phone call we're going to get from the school. We get report cards that say, "He could do better if he concentrated or tried harder," and we want to rip up the report cards and scream, "What do you think the diagnosis of ADHD means? Why do we even bother telling you our child's diagnoses and problems if you're going to say such things?" Or we go to team meetings or CSE meetings and hear a litany of problems -- sometimes expressed with concern, sometimes expressed with frustration or indignation on the part of school personnel. Some of us seldom hear a positive word about these children whom we love dearly and who can be so very different under different circumstances.

What's it like for us? Some of us live with a sense of dread that sometimes borders on terror because we don't know what that next waxing cycle will be like and whether our child will be totally out of control of their body and mind. And we look at our children suffering and feel powerless to stop that suffering even though we'd gladly give our right arm to give them some relief from the tics or compulsions that torment them or the rejection they may experience. When things are really bad, we try to remind ourselves that we should be thankful that our child doesn't have cancer, AIDS, or some fatal illness, but it doesn't really help. We cling to hope that our child will be among the lucky ones whose symptoms will ease up later on and who will have productive and happy lives. But in the meantime... in the meantime, we are watching our children suffer -- because their tics are driving them crazy or because they can't get a thought out of their head or because they have to do something over and over again even though they want to stop -- or they're suffering because someone has made fun of them for their symptoms -- or because some adult who they trusted has told scolded them that they could control themselves or that they could do better if they only tried harder -- or because their teacher has made them feel that their presence is a disruption or a problem.

In a little while, Sue will take you through an exercise that will give you a small taste of what a child with TS experiences in school. It may help you understand that living with TS and its associated disorders can take a toll on our children -- whether it is fatigue, irritability, inability to concentrate, or depression -- and that you may only be seeing the tip of the iceberg.

Yes, we know our children aren't convenient for you to educate. They're not convenient for us to parent. But they're here, and their problems aren't their fault. They need us working together to support them and help them. And we need you to understand that as much as having our child in your classroom may be taking a toll on you, parenting this child is taking an even greater toll on many of us. All too many parents land up overwhelmed, exhausted, and/or depressed from trying to help their child function or cope with school. As strong as I am, I landed up in a depression after a few rough years of dealing with my son's school and psychiatric problems. And after living through periods where he was suicidal and literally on suicide watch, and having had to go back time and time again to his district to try to get him the help or services he needed, after spending hours and hours of time and emotional energy fighting for simple accommodations

like a damn computer because he can't write by hand, and having had to finally go to court to get him the educational program he needed, it all caught up with me. And I'm actually one of the lucky ones, because through it all, my husband and I were a partnership. I know many couples that are ripped apart by their child's symptoms and problems. I get calls from mothers every week whose marriage is on the rocks because the conflicts over the child are more than the couple can handle. And it is often the school problems that triggers the most devastating fights between the couple.

There are many mothers like me -- mothers who will come to you because they're worried about their child and about how their child's school experiences are affecting him or her. Instead of suspecting that maybe the parent is overanxious or exaggerating, if the parent is there, if they're involved, if they're being responsive to your notes and calls, then try assuming that the parent is giving you accurate information about what they're seeing in the home. And realize that school is, indeed, a major source of stress for children with TS or TS+ but that the signs of that stress may not be showing up in school.

I know that there are parents who unfairly blame the schools, just as there are teachers who unfairly blame the parents. And I know that the parents need to listen, too, and understand that what the teacher is seeing may be different because of the different settings. But it's the blaming that's the hardest thing to get beyond. The blaming is born of ignorance -- whether it's ignorance born of lack of education about how TS+ can impact a child or whether it's ignorance born of lack of recognition that in our respective roles as parent and educator, we only see the child under one set of conditions. Sometimes I think that we are like the proverbial blind men with the elephant. Parents, educators, doctors -- we all see only a part of the elephant.

Educating children is a partnership between parents and educators. If that partnership is only lip service or on paper, it's not going to work.

So..... what is the parent's perspective? We need you to see a bit of what we see -- we need you to be able to see our child and not just his symptoms. We need you to understand that just because you don't see things in school, it doesn't mean it's not going on. We need you to recognize when you're looking at a symptom and not a voluntary behavior. We need you to listen to us and believe us when we tell you how our child is outside of school or how school is affecting him in the home. We need to be talking about the same kid or we'll never be able to help him.

Thank you.