

The Role of Structure in Parenting a Child With Tourette Syndrome

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In my counseling work with parents of a child with TS, I frequently stress structure as an essential component of parenting skills. But what does structure mean in terms of parenting — what does it “look” like in the context of a family? This article will attempt to look at structure in both conceptual and concrete terms, in hopes of providing parents with an understanding of this important “tool” of parenting.

The concept of structure in families has long been explored by family therapists who see it as a way of understanding how families work (or don't work). They explain families in terms of systems, sub-systems (smaller, unified groups within the larger system of the family, e.g. the “sibling sub-system”), and boundaries. Families are often described as “enmeshed”, meaning that boundaries between sub-systems are too permeable, or “disengaged”, meaning that there are no open lines of communication between family members.

Before looking into how this way of conceptualizing the family can be helpful to parenting a child with TS, it is important to identify some of the particular needs of these children.

Children with TS tend to be bright, but they also tend to be quite disorganized. They could do their homework without a hitch in 20 minutes if they could just concentrate for that long.

The fact is that there is a lot distracting them that kids who don't have TS don't have to deal with, i.e. the tics as well as (in some cases) the associated behavioral problems: attention deficit disorder, obsessive-compulsive disorder.

Many of these kids also have an oppositional streak, giving rise to behavioral problems. A request to shut off the TV or to clean up their room can precipitate a battle of wills that may escalate into a shouting match.

Situations like these often give rise to that age old question: “Is it Tourette, or is she/he just misbehaving?” In some instances, this may be

an important question, but for the topic at hand, this question is moot.

A more pertinent question is: “What do we as parents want for our children? Don't we want them to be able to organize their time efficiently, to be able to complete their tasks with the least possible frustration?” In short, we want these kids to travel through their developmental phases as smoothly as possible. Using structure effectively means using the authority of parenthood to help our children meet these ends.

Recently, a single mother of two young children came to my office for a consultation. She appeared terribly worn out as she told of how her children (the oldest of whom has a mild case of TS) ran her ragged. After awhile I asked her how decisions were made at home, and she told me that she valued a democratic system wherein each family member had an equal vote. The problems arose when she wanted her two kids to do something they didn't want to do. They simply out-voted her.

I think we can all appreciate this mother's intention to involve her children in the decision making process. Most of us want to encourage independent thinking, and therefore try not to create a family environment that is too restrictive. We fear that a highly structured family may stifle our children's creativity.

Our experience is that the reverse is true. Paradoxically the highly structured family is one wherein children feel that they can safely experiment. The parameters (or boundaries) are sturdy; that is, they have a sense of how far they can go. They know that if they transcend a boundary, their parents' judgment will protect them.

In the example above, we see a case where the sibling sub-system had decision making power equal that of the parental sub-system, thus undermining the inherent executive authority of the mother. Her children's excessive trouble making can be interpreted as a plea for her to take control and make some rules.

In structural terms, one of the tasks of the parental sub-system is to

make-up and institute the family's rules. When a parent does this, it takes the burden of determining where limits are set off of the children themselves.

Thus we have an important component of structural intervention: consistent limit-setting. Another case example follows.

The parents of an 11 year old boy with TS brought him in for treatment, as he was constantly misbehaving at home. The initial interview yielded the information that he did well in school, both academically and behaviorally. The boy himself had little insight into why he behaved poorly at home and in fact was always pleasant and well-mannered during our sessions.

The first thing we did was to set up a behavior modification program (punishments/rewards based on the completion of certain tasks). This worked for a little while, but he soon went back to his old ways, and with added vehemence. Clearly, the motivation that we offered wasn't what he was looking for.

While this was going on, his parents and I were looking into the ways they handled his misbehavior. It soon became evident that the punishments which they meted out had more to do with how they were feeling than the offense itself. If they were exhausted, they were extremely lenient. If their son had done well on a test, they tended to let him disobey. Mom was usually more tolerant than Dad. In short, the boy had no way of knowing what to expect from his parents.

Once this was pointed out to them, his parents instituted consistent limits (for the most part — nobody is 100% consistent). Their son's behavior has begun to improve markedly as he now has structural guidelines as to what is accepted behavior.

Another mother recently called to discuss problems with her 12 year old son's schoolwork. At school, his day was highly structured (as a result of the Individualized Education Plan [IEP]) and he did well in that context. The problems arose from the fact that he rarely did homework.

His mother called to question whether she should monitor his homework. Her instincts told her that she should; however, she hesitated. Her thinking was that his school environment was structured enough. Shouldn't he be able to

structure his own time at home?

Of course, ideally, he should. But most 12 year olds, and especially those with TS who have been controlling themselves all day, will not self-impose any restrictions at home. In fact, whether they are aware of it or not they look to their parents to set the limits.

In the case at hand, the boy did need some unstructured time to unwind after school, so the plan we came up with included an hour after school before he had to do his assignments, which his mother checked once they were complete. The idea here was to create a structural framework that had unstructured time within it.

These examples may appear as burdensome to parents. Does imposing structure mean that we as parents have to become policemen and women?

While this may at times seem to be the case, it is in most instances a short-term investment that should yield long-term results. Children look to their families to give them a sense of security as well as a sense of propriety. It is largely through their

familial experiences that they gain a sense of belonging, an identity. In other words, the family is a conduit for socialization.

In this light, the need for structure becomes particularly salient in today's world, where society's mores are constantly coming into question. It must be harder and harder for our children to develop a clear sense of values as society becomes more and more complex raising ethical questions that have no "right" answers.

It is in this context that our children look to us, not for a rigid point of view, but for firm parameters within which they can learn to make their way in the world, TS notwithstanding.

In summary, kids with TS tend to need a lot of structure, both in school and at home. To use structure as a parenting "tool" means to use the authority vested in us as parents to set consistent limits and to demarcate boundaries within the family. This will help to create a family unit characterized by established guidelines, affording children a secure backdrop against which to grow.