






## Parenting: Disciplining a Child with PDD

(BBB Autism printable article #21)

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-  Family strife
-  Discipline
-  Problem behaviors

There's a parable about accepting children with disabilities that regularly makes the rounds of support-group newsletters and Internet discussion groups. Written by Emily Perl Kingsley, "Welcome to Holland" (Kingsley, 1987) talks about the experience of planning a trip to Italy but accidentally ending up in Holland, which doesn't have the Coliseum or Michelangelo's David, but does have lovely tulips and Rembrandt. Holland is different, but it's good in its own way--just like your child with a disability.

While many parents have found this fable comforting, others feel patronized by well-meaning advice and reading material that encourages them to simply accept their lot.

*"I look at that **Welcome to Holland** pap piece and think, 'What the hell do they mean? Try 'Welcome to Bosnia!'" --Krista, mother of seven-year-old Joshua*

When you are encouraged to accept your lot, even to see it as a gift, it can make you think you don't have the right to be mad--but you do. No one deserves to have these disorders, and no one deserves to have their lives turned upside down by caring for someone else who does. On one level, you do have to accept the situation. On another, you cannot, and must not if you are to have the energy and determination to help your child.

You may feel surprisingly angry if you're told that God or has chosen you for the "special" duty of parenting a child with a disability. People usually mean these words as a compliment, but they can add to internal feelings of being trapped in a role you never asked for, and to feelings of inadequacy.

And as Krista's comments above indicate, a PDD diagnosis can turn family life into a battlefield. Looking at the carnage through rose-colored glasses isn't always an option.

### **Family Strife**

Mary Callahan's book *Fighting for Tony* is a fine portrait of how a PDD diagnosis can affect a family. Whether you agree with Callahan's theories about the causes of her son's autistic behavior or not, her description of a marriage's disintegration under pressure will be sadly familiar to many parents of children with PDDs. As her son's mysterious illness pitched the Callahans into repeated battles with doctors, the school system, and each other, a solid and loving relationship was destroyed by the pressure. This true story has a happy ending--not only did Callahan "recover" her son, she and her husband eventually recovered their marriage.



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Another poignant portrait of autism's effects on the family is Family Pictures, a novel by Sue Miller. Later made into a very affecting TV movie, Family Pictures chronicles the dramatic impact of an autistic son on his affluent Northeastern family.

Both Callahan's real-life account and its fictional counterpart demonstrate the same point: the word "pervasive" in pervasive developmental disorders describes the impact of these conditions on the people around the patient, as well as on the patient himself.

*"My marriage has definitely suffered, also my relationship with my older daughters. I find it difficult to keep it all in perspective." --Lesley, mother of three-year-old Danielle (diagnosed PDD-NOS)*

Every family is different, but there are a few problems that many have in common. These include:

-  Differences over discipline
-  Inability to handle problem behaviors
-  Withdrawal by one parent, or by one or more siblings
-  Over involvement by one parent
-  Burnout
-  Resentment
-  "Genetic blame"
-  Parental neuropsychiatric problems
-  Breakdown of extended family relationships
-  Community isolation
-  Financial problems related to disability
-  Sibling rivalry compounded by behavior problems

## **Discipline**

Perhaps the number one problem in any family with children is differences of opinion about what constitutes appropriate discipline. These are only compounded when a child has a neuropsychiatric disability. The behavior problems are bigger, and solving them is more difficult. Conflicts between parents become more likely.

Uncontrollable tantrums or rages in an eight-year-old, self-injurious behavior, assaultive or destructive behavior, and communication problems between parent and nonverbal child were not dealt with by Dr. Benjamin Spock or Penelope Leach. Grandparents and friends haven't a clue. The usual strategies may not work at all.

In particular, spanking and other forms of corporal punishment often seem to feed the parent-child conflagration. For one thing, autistic-spectrum people often have unusual perceptions of pain. There's a danger that getting through to the child with a smack on the behind won't work, and parents may then be tempted to go too far with physical punishment. In addition, hitting can reinforce a child's assaultive or self-injurious behaviors. For these reasons, parents are strongly advised by almost every expert in autistic-spectrum disorders to find alternative methods of discipline.

### ***And therein lies the rub.***

With "normal" children, rules, reasoning, brief time-outs, and an occasional docked allowance will usually suffice. What do you do when the child can't follow your reasoning or puts up a wall that you can't get through? This is a struggle for any parent, and when two parents are at odds it only gets worse.



It's very common for one partner to have a lower tolerance threshold, or a smaller repertoire of effective, nonviolent discipline strategies. This is where the arguments begin. One parent lets a behavior go, while the other is hugely annoyed by it and eventually blows up. One parent spansks, and the other rushes to comfort the child. One parent gives a time-out, and the other adds a second punishment because that doesn't seem like enough.


*"My husband and I had trouble for several years because he did not want to admit that our son had a problem. It was just too much for him to face. He felt that strict discipline would overcome the hyperactivity and the short attention span. Finally, after my son regressed to the point that he didn't want to be touched and couldn't find his way around, [my husband] came to the party." --Kim, mother of seven-year-old Brad (diagnosed atypical PDD, cognitive epilepsy/Landau-Kleffner syndrome)*

Differences over discipline are often deep-seated. Most of what we know about raising well-behaved children we learned our parents, for better or for worse. Chances are that not only were your parents imperfect disciplinarians at best, but also weren't raising children with PDDs. Techniques that worked you, as a youngster may be totally inappropriate for your child.

The first key to resolving discipline disagreements is making a compact between parents. Behavior experts who have worked with families affected by a wide variety of neuropsychiatric disorders agree that this compact should include, at minimum, the following points:

- The best discipline is positive, so parents must rely on providing incentives for desirable behavior before using punishment to control undesirable behavior. The "token economy" schemes used in many classrooms can be successfully adapted for home use, for example. Parents should also learn about alternative strategies for addressing the roots of problem behavior, such as relaxation techniques.
- Punishment must fit the crime. Whenever possible, the only punishment should be experiencing the natural and logical consequences of an undesirable action. For example, if Joe bites his friend Jane, Jane will go home. If Joe pours his juice on the table, Joe has to clean it up and does not get another glass of juice.
- Parents must agree on basic guidelines for stopping undesirable behavior, such as whether physical punishment is ever acceptable, what form discipline will take, and under what circumstances it will be meted out.
- If physical punishment is ever to be used, it should be a last resort and used in a controlled fashion.
- Accordingly, parents must come up with a common set of effective disciplinary measures for undesirable behavior. These may include loss of allowance or privileges, addition of chores or other responsibilities, time-outs, and, for older children, grounding.
- Parents must agree to avoid calling the child (or each other) hurtful names or using other verbal abuse.
- Parents need to support each other in the effort to remain calm during behavior problems. If a parent is losing control, he or she should feel free to turn the situation over to the other partner long enough to take a "parental time-out."
- Parents must not, however, give one partner the permanent role of disciplinarian. The old "wait 'til Daddy gets home" scenario lets one parent off the hook, and encourages children to be fearful and manipulative. For children with neurological problems, delayed discipline can be particularly confusing.
- If an undesirable behavior happens repeatedly, and neither incentives nor disincentives seem to curb it, parents should agree to look closer for hidden causes. Behavior analysis techniques can be very useful in this regard.



 Most importantly, parents must present a united front, even when they don't actually agree. Arguments over discipline should not occur in front of the child. If Mom thinks Joe needs a time-out for throwing blocks, but Dad thinks a reprimand is sufficient, Dad can let her know how he feels while Joe is in time-out. Next time it happens, they'll be in full agreement about the proper consequence for throwing things.

Parents do need to remember that people with PDDs may respond to discipline unevenly. A child who has rages that arise out of seizures or other neurological events may not be able to gain self-control at these times, but can do so when the behavior is a garden-variety temper tantrum. People with PDDs may perform acts compulsively and be unable to control these actions by force of will alone. Interventions may have to include protective devices, security measures, and medication.

The bottom line is that you know your child. To be effective, the discipline plan you create must be individualized, and must be flexible enough to take into account the child's mental and neurological realities.

### **Finding Help**

These skills do not come naturally, so the second key to defusing the behavior time bomb is finding expert assistance. Behavior modification professionals, ABA practitioners, family therapists who are knowledgeable about neuropsychiatric disorders, and others can help. Usually the professional should observe the child interacting with parents and siblings at home, preferably more than once.

These professionals can help with both an overall behavior plan, much like those used in schools and with specific suggestions. The best experts can be available on a long-term basis, providing parents with someone to call when they run out of ideas or patience. A good family therapist can be of particular help when parents do not agree about appropriate rules and discipline.

Your special education case manager, government mental health or developmental disabilities department, psychiatrist, or provider should be able to help you find professional help for behavior management.

### **About Time-outs**

For most children, time-outs are an effective way to gain the child's attention, make it clear that a behavior is undesirable, and attach a consequence to a behavior that doesn't have built-in natural and logical consequences. For some children with PDDs, they are very effective.

For others, they are not. Children who are severely socially withdrawn may actually find time-outs to be reinforcing. For these children, ABA and behavior modification techniques are a better choice.

You may want to modify your time-out procedure to take your child's special needs into account. For children who have trouble with time concepts, for example, a timer or stopwatch can help children who are often given time-outs to deal with frustrated, aggressive behavior may need a space with pillows or foam bats they can safely bang around. Some families have cleared out a closet for a time-out space, removing the clothes bar and any other potentially dangerous items and adding a punching bag, beanbag chair, and other items that can help a child work out angry feelings.

***(Note from BBB Autism: although this is on the whole a great article, we in no way advocate putting your child in a closet – for any reason!)***

### **Parenting Classes**

Parenting classes may or may not be useful. Parent Effectiveness Training, Positive Parenting, and similar courses are designed for children whose responses fit the predictable pattern. When a child has PDD, his response to a particular



incentive or disciplinary measure may not fit the mold. For example, a child may not be able to grasp the concept of natural and logical consequences until a much later age than expected. As noted earlier, corporal punishment may be ineffective or counterproductive. Reasoning with a grade-school child who has a PDD may be a useless exercise. The incentives that motivate "normal" children may be of little interest.

*"My son's day treatment center required parents to attend a weekly skill-building group. I'm sure it was valuable for some of the families, but it just gave me a regular reminder of how far out of the mainstream we were. When I asked my first question, it was about how to handle a child in an out-of-control rage. The teacher asked me to explain what I meant. When I started talking about a child who turns bright red, falls to the floor, bites anything in reach, and can't be calmed for as long as two hours, she blanched and said, "Gee, I don't know ? maybe you should ask a psychiatrist." The psychiatrist, of course, had suggested that I bring up the issue in my parenting class.*

*We never have gotten a good answer. We definitely need parenting skills that are different from what worked with our daughter. Who can tell us what we should be doing?"*

Sometimes parenting classes geared to the special needs of families with disabled children are available through local hospitals, Early Intervention or special education programs, or disability support groups. Depending on the instructor's skill level and approach, these can be very valuable.

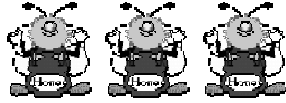
## **Problem Behaviors**

What do you do when your child has a behavior that you (or your partner) simply can't handle? Echolalia, weird noises, constant humming, head banging, pestering the pets--whatever it is that makes you flip your lid, your child with PDD-NOS or atypical PDD will probably find it.

If it appears to be something neurological that you'll just have to live with for a while, try dealing with your reaction rather than the behavior. Try earplugs, a Walkman with headphones, asking your partner if you can go for a walk for fifteen minutes ...whatever it takes to keep you sane. Likewise, if your partner is the one being driven up the wall, be willing to take over for a while and let him avoid the annoyance.

Alternatively, change the situation to avoid the annoying behavior. If your child's fine-motor problems lead to atrocious eating habits that turn your stomach, have a kids' table and an adults' table at dinnertime, or two different dinner times. Or serve the child foods that are harder to make a horrible mess with. Try relaxing your standards a bit--Martha Stewart does not have an autistic-spectrum child at home, so you really shouldn't try to compete with her in the creative housekeeping department. Get a sitter instead of taking the child with a PDD to a fancy restaurant, or choose restaurants where being messy is no big deal.

Be creative in your solutions, and don't worry about whether your family's way of coping is "normal" or not. Go grocery shopping at midnight, order clothes from catalogs, put a lock on the refrigerator, set up a cot in your room for your child who has night terrors. If it works for you and harms no one, it's all right.



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*"Our son is almost eight, and he still sleeps in our bed almost every night. I brought this up hesitantly in my email chat group, and found out that we are far from the only parents who allow this. He seems to need the extra contact, and he sleeps through the night consistently."*

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