

Introduction

by Lisa Carver

I came home to find a police car in my driveway.
Again.

I knew they'd be there, from the message on my cell. My son Wolf's home aide called them when Wolf: A. started growling, B. tore his homework to bits, C. trampled the flowers he'd planted, and D. hurled himself repeatedly against the door, saying he didn't belong in this family, in this home; he was going to live in a tree.

Because my son hating himself or lacking adroitness in managing frustration, whichever you call it, was such a part of my life, that wasn't what I was focusing on when I got the call. Experience had taught me that what I needed to concentrate on right then was how I looked. Because the consequences that would result—for Wolf and for me—would depend on how well I could translate for him, explain the destructive things he does and reassure the stranger holding authority over our fate that we were doing all we could to get it under control. And how believable he would find me would depend on how serious, how **normal**, he found me.

When you have a special needs child, it's your attitude on trial, your lifestyle, and the judge and jury is every "helpful" stranger/family member/professional in the world.

I did the mental checklist. Did I happen to pick out conservative clothes today? Check. Tattoos covered? Check. Okay, now exit the vehicle with grocery bag in hand, so obviously I wasn't out doing jolly or countercultural things when I **should** be doing games and therapy with my child to practice the social/physical skills/reactions that don't come naturally to him.

I tried to maintain eye contact while explaining that Wolf has the mental capacity of an eight year old. The officer explained to me that he is not

eight, he's thirteen, and at his age he could be charged with assault or malicious destruction of property.

I said, "It's his property he destroyed. It's himself he assaulted. Life is hard for him."

"You're making excuses for him," the officer replied. "Keep that up and your kid is going to end up in jail."

We don't make excuses. We make explanations. To all the people who don't know. To the people who have power over our child's life, and ours. Which is everyone. Our special child's peers, surgeons, therapists, teachers, guidance counselors, insurance companies, home aides, camp officials, independent living center directors, our own families. Sometimes we plead. Sometimes we threaten. Sometimes we hold it together and someone is actually listening. But there's only so much they can do.

We are tired. Something works, ten other things fail. You try everything, and eventually you burn out. Which can be a good thing. You start trusting yourself, trusting your child. My son got the short end of an awful lot of sticks, and no matter how hard I keep tugging on the other ends, those sticks ain't lengthening.

Not to take away from the value of when he was younger, when I was still a hopeful zealot. That is absolutely necessary. At some point, you will give up trying so hard, and come to trust yourself, trust your child, trust what *is*. But if you haven't beaten your head first against every wall, if you haven't tried until you cry for what *could be* you haven't done your job.

Still—it sure does help to have some acceptance and encouragement and commiseration along the way.

And along comes the Short Bus.

The various authors in this anthology may not have any cures to offer, but they have something infinitely more valuable: no cures. Understanding. They, too, have experienced society's impossible-to-fulfill expectations (demands) for parents of special needs children.

1. For actions: We must do everything we can to help our children to change what is different about them, make it *undifferent*, so they can integrate, so they can be as normal as possible. (To do that, *we* need to be normal first.) We must reprogram our children, go against their nature, go against nature itself. Constantly. It would be considered emotional abuse to do that to a "normal" child, to tell them every day in many ways they cannot be who they are.

2. For attitude: What can't be changed, we have to look at as a gift, *God's way of teaching us patience*; God gave us this child because *He* knew we had enough love to handle it. (To keep that positive attitude up in the midst of all this crap, one would have to be a total hypocrite, or on massive amounts of Xanax.) We are not allowed to be angry.

For our child, there are therapy, surgery, medication, and aides (home and school) aimed at achieving that first goal.

For *our* attitude, there are guidebooks and memoirs to help get that one right.

This book is not one of those.

You're not wayward here. Here you don't have to fight the outside world, and you don't have to fight the inside world of other parents of special needs kids with whom you have only that in common. The authors here are different in different ways—some by politics, some by orientation, others by poverty ... all by attitude. Here, we don't say what we think one is supposed to say—we say what we know. Even if it's, as Christina Witkowski, whose child has spina bifida, admits: "Sometimes I hate being the parent of a special needs child." Or as Amy Saxon Bosworth jokes, she's sick of being told her three (!) special needs children are gifts, "like [I] won some disabled kid lotto." Of course, these moms love their children just as much as the ones who call them little angels ... maybe more so, because they are honest and brave enough to get *all* the truths off their chest, not just the ones we're *supposed* to feel, and so they can see their children for who they are.

This is for you, the outsider parent who already didn't look at the world the way others did, and happening to have a child with, say, autism, is not going to make you suddenly able to relate to the attitude held by other parents and specialists of other autistic children. Of course you want to help your child to be a success. It's simply that you may have different ideas about the definition of success.

"If everything was beautiful and the same," explains Sabrina Chapadjiev's mother Magdalena, "it wouldn't be life."

So please, come ride this awkward Short Bus, where no passenger is alike, where there is no Right, there is no Truth. There are only some unusual, sometimes unpleasant, sometimes incredibly pure and beautiful, little truths. And, to paraphrase Tiny Tim in *A Christmas Carol*, God bless us, every fucked-up one.