

## **Essay: Look Through the Windows of My World"** **By Pat Linkhorn**

### **An open letter to educators from parents of children with special needs.**

This "open letter" is, of course, not representative of all parents of children with disabilities, but I've tried to make it a fair sampling of the views I've heard expressed from other parents. I know I won't live to see Utopia and my children probably won't either, but the laws that are being passed today providing inclusion of children with disabilities into public schools give educators the opportunity to make this a generation of better people. And that's one step closer!

You can't walk a mile in my shoes, but take a short journey with me and I can show you scenes from my life. You're the person responsible for my child's education - a superintendent, a principal, a teacher, a guidance counselor or a special education director. The object of this is not to make you feel sorry for me. It's to try to help you understand me and my child. If you can understand something about the places I've been, you may be able to understand where I'm coming from today.

This first window shows you a death. It's not a typical death. We didn't get flowers or have calling hours. It was a very private affair and not too many people even realized it at the time. This was the death of a dream. You see, I always thought I'd grow up, marry and have a couple of "normal" children. When this death occurred, and it doesn't matter whether it happened when my child was first born, or as he began to develop. My whole life changed. I hadn't planned to have a child who had to use a wheelchair, or who would never be able to hear or see, or who couldn't "pass" a standard I.Q. Test. I was forced to change my whole outlook on the future. It may have taken a while to go through all the stages I had to go through to get to where I am today. There was grief – a whole lot of that. There was a lot of denial, too. I had to get through those two stages before I could accept what had happened and accept my child and the limitations he would put on my dreams. I had to come up with a new dream.

This next window shows me after I've learned to accept my child for who he/she is. I've learned to take all the backward glances and tasteless remarks in stride. I've seen ignorance from some people I used to think were intelligent and I've met some really wonderful people who I never would have known, had my child been normal. I've had to learn how to make people understand that my child is a child first and disabled second. I've seen miracles too. I've seen the first step the doctors said would never happen and I've seen the light of recognition in my child's eyes when he finally grasped the "meaning of something". And, I've seen sunsets you wouldn't believe once I had to really look at them and explain them to my blind child. What may seem ordinary to you has taken on a whole new significance for me. I've learned a whole new language too. It's called "medicalese". Doctors tend to speak in words you don't hear every day. At first, I thought I'd never be able to keep all the terms and "isms" straight, but I speak it fairly fluently now. I'm beginning to learn "teacherese" now. You use a lot of abbreviations and numbers, but I know I can learn your language too.

Even though I've accepted my child, this next window will show you my fears for my child's future. I realize it's going to take a lot more effort if my child is to lead a fulfilling life. Learning may be difficult for him and in some cases, impossible, but I've really been trying to make his life as normal as possible. I try to focus on the abilities he has and I try to make him feel worthwhile. I realize there are some things that my child can't do yet and he may never be able to do some things. Sometimes, I tend to focus too much on what he can do and not what he can't do, but it helps me and my family. Some days I seem to be taking three steps backward for every one forward. You may only see the bad things about my child. It may not seem fair to you to spend more time with him or do things differently for one child, when you have a class room full of children who learn things in standard ways. My child may disrupt your class. He may not seem to be learning much. I don't expect you to ignore other students for his sake. I don't want him forgotten in a back class room with all the other "different" kids either, although he may have to

spend some time in a smaller class room with more individual attention. My goal is to make his life as normal as I possibly can, and being around non-disabled kids helps. It will take some understanding on both our parts to work this out. Perhaps some of your brighter students could help my child in some areas. You'll be teaching them about responsibility and they'll learn acceptance. They'll view disabled children as children first and disabled second. They may learn to accept my child before you do.

As a parent, I know I'm not perfect. I make mistakes every day. I realize teachers are only human too. I also remember the time when some of my teachers were up there with God, in my estimation. They had such an impact on my life! Your lives probably aren't as worry free or stress free as I used to think and my child may only add to a day that's too full and too underpaid. If you at least make the effort to try to treat my child as a person, I know how he will view you. Sit next to God for a while.

My attitude may not be the best you've seen lately. I may already have had some run ins with the "system" before I ever talk to you. I may come on too forcefully and seem too demanding. Maybe I've had to be to get services for my child. Maybe my sister-in-law has excluded my child and I from every family get together she's had since I've had a "disabled" child. Maybe my husband isn't supportive. Or maybe the professionals I've dealt with before have done everything they could to help me. Maybe I'll assume that you will too, and I won't remember all the hard lessons I've learned along the way. Or I may remember each one too vividly. I may be a combination of all these feelings. Whatever the case, I am just a normal person who wants the best for my child.

I probably already know that my son won't grow up to be the captain of the foot ball team and my daughter won't be a Home Coming queen, but that doesn't mean that I don't have dreams for them. I've just substituted other dreams for those I've lost. We all harbor some pretty unrealistic expectations for our children and I'm no different than any other parent.

If I seem to want too much from you, I don't mean to. I may have a lot on my mind. I may not have totally accepted the direction my life has taken; it sometimes takes years for a parent to get to that point of acceptance. That's really not too hard to understand when you realize that I lived with that dream for most of my life, whereas I've lived with my "reality" for a lot shorter period. I may even be feeling cheated because my life seems so different from yours. There may be a lot of resentment in me. Or I could just be tired of fighting the battle. It may be that you have a better education and you may feel more qualified to make decisions about how and what my child will learn. In most cases, you are the expert. But if you feel I'm realistic and I've accepted my child's limitations, there will be instances when I will know what will work best. In that case, I am the expert. I've learned some things that you should be thankful you've never had to learn.

If you take all the things you've seen through my windows into consideration, you may understand me and my child better. If we work together, maybe we can do what I pray for each night. That is to give my child as many opportunities as possible to lead a normal life, in a world that isn't fair.

Pat Linkhorn is a professional advocate for families with children who have special needs. She is also an experienced parent and has two girls with special needs - autism and blindness due to prematurity.

**"Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it's the only thing that ever has."**

**-Margaret Mead**