

You Can Make A Difference In Our Lives

(Thoughts to professionals from a parent)

Excerpts from *It Matters: Lessons from My Son* (1997) by Janice Fialka

Permission granted by Janice Fialka.

I believe that as professionals who work with children with disabilities—educators, therapists, social workers, physicians, and so on—you can make a difference in our lives as parents of children with special needs. You cannot, however, make *THE* difference. Therein lies the challenge of our partnership. Highlighted here are ten ways in which you can make an important difference.

ONE: You have the opportunity not to be frightened by our anger...to embrace it, to welcome it, and even to invite it on a good day. Obviously, you cannot do it every day. You have the opportunity not to be intimidated when we blow off steam. You have the opportunity not to personalize these angry, negative feelings. The great challenge for you is to give us the opportunity to fall apart once in a while. You may be surprised by how quickly we recover when we are given the opportunity to feel our feelings in the company of experienced and caring professionals.

TWO: You have the opportunity to decrease our profound sense of loneliness. You have the opportunity to break that silence and gently lead us into the sounds of compassion and respectful curiosity. So often we want to talk about “it,” but few people appear to want us to talk. You often will be the ONE person who will say: *Tell me more. And then what happened? And how did that feel?*

THREE: You have the opportunity to anticipate and normalize our feelings. You can prepare us for the challenges of birthdays and holidays. You can let us know that we will have wild mood swings and uncomfortable thoughts about “those parents” with normal children. Never underestimate the significance of your anticipation and acceptance of our feelings. It will comfort us during those long sleepless nights.

FOUR: You have the opportunity to help us re-enter the “world of normal families.” Parents with special needs children never feel the same once they learn about their children’s differences, especially when the differences are cognitive. We don’t know how to squeeze back into the world despite the fact that we are in it. Going to a birthday party can be a major mountain to climb. You, as the professional, can create bridges back to that world.

FIVE: You have the opportunity to help us know our child. In the beginning, most of us know very little about the disability or special needs. We often can’t even spell this new reality of our lives. You can model for us how to say the words, how to tell others. You can take us into our children’s lives.

SIX: You have the opportunity to share books, pamphlets, and other resources. Take those books and articles out of your file cabinets and off the shelves and share them with parents who have no idea where to find the stories and facts about their children. It is very challenging to walk to the “disability” section of a bookstore or library. You can bring it to us and even sit next to us as we tentatively open those pages.

SEVEN: You have the opportunity to recognize and celebrate our victories. They are often too small for the “normal” population to appreciate. You know that the awful sounding “grunt” made by our child is truly a miracle. Only you know that a new movement is significant and indicates a renewed sense of hope. You can point out these grand milestones to us.

EIGHT: You have the opportunity to remind us how far we have come and how much we have accomplished. You, often more than our closest friends, know the details of our successes. Over and over you can highlight those changes and celebrate the growth.

NINE: You have the opportunity to allow us those moments when our souls fall into deep despair. We will at times feel that we *cannot* continue for another moment. We will at times feel that we *don't want to* continue for another moment. You can give us the space to be in that dark place. It is one of the greatest "interventions" you can provide.

TEN: If at times you can do some of these nine suggested activities, you will then have the opportunity to help us feel hope. We must feel hope if we are to get to our next appointment, or to face the next birthday party, or to use the words "special needs."

Effective partnerships between parents and professionals require collaboration. Plopped right in the middle of that word you will find the word "labor." Partnership is labor. It is hard work. You are the midwives helping us give birth to a new relationship. Let us begin.

