

FEELING MISUNDERSTOOD

I HAVE SPENT A LOT OF TIME thinking about you, the reader, and about your child. I imagined sitting with you on my deck looking at Mt. Hood or the fog that might be blocking it. I would share the successes and failures along my journey as Billy Ray's mom. Mostly I would listen to you vent, because that is probably your least-met need. The pat answers given to parents would only leave you frustrated, so I would avoid those. There would be comic relief sharing stories of how we have felt misunderstood by even those we expected to understand and the cute things our kids had done. Above all else, you and I would both feel some familiarity with each other's situation. We would be kindred spirits—which are not so easy to find when you are raising a complex child.

Parenting any child is challenging. When some difficulty such as an illness or disability is present, it is even more so. When you have a complex child who tends to challenge even the medical and educational pro-

professionals, solutions involve more than technical procedures and professional advice. They also involve patience, endurance, frustration, and much self-control. The irony is that often your child may cause you less frustration than those involved in his care and education. Much of the time it feels like no one really understands, including the people you expect to be the most understanding: professionals and your closest family and friends. The sense of isolation from the rest of the world, including sometimes your spouse, can be lonely and painful.

You may feel judged by people you know have no clue what a struggle your day-to-day life is. If your child wears dirty clothes to school or the doctor and is not freshly bathed, it appears that you do not take proper care of your child. In reality, it may be that your child refuses to change clothes or bathe. If he behaves inappropriately, he may appear undisciplined when in reality he is confused. If you do not correct him, you may be accused of spoiling him. Often when you take your child out of his environment, even to the doctor, he will behave entirely differently than at home. Billy Ray often behaves better in public than at home because he is frightened. That makes it even more difficult to gain understanding from others. Surprisingly, even parents of other disabled children may not be able to identify with your situation.

You may go through life feeling exhausted, sad, frustrated, or angry. If you are angry with school or medical personnel, people just assume you are grieving or in denial regarding your child's disability. Certainly, parents do experience grief and denial that might manifest itself in angry outbursts at meetings. However, frustration at trying to be heard or get appropriate services for your child may be the cause of angry outbursts as well.

Instead of feeling good when someone says, "I wish other parents cared for their children the way you do," it makes me sad and even angry. I do not believe that I care about Billy Ray more. It is my belief that the very systems set up to help our kids often defeat the parents. Nevertheless, if parents do not come to planning meetings or follow up on appointments, they may be accused of not caring.

LEFT OUT IN THE COLD

I will deal with this point more fully in chapter 13. For purposes of this chapter, I would like to give you just one example of how the system

often defeats the parents. I had been working with the autism specialist to create a more workable school schedule for Billy Ray, because school was not working out well for him. The specialist visited with folks in the school building to research projects that might be available for Billy Ray to do, similar to those Billy Ray had done in his most successful year. The specialist created some communication cues and other materials to help Billy Ray understand tasks better. I was pleased with the ideas created and anxious to share them with the Individual Education Plan (IEP) team at the scheduled meeting. I was sure it would make things better for my son.

I walked into the meeting to find that the entire team including the county case manager had convened a half-hour early for something they called a “premeeting” (a meeting held to plan the meeting before the parents arrive). The autism specialist had presented the plan to school personnel outside of my presence and the school personnel had decided that they could not provide that much structure in their program. The decision to remove Billy Ray from the program was made before I walked through the door. My vote in the matter was of no impact by the time I arrived. There was nothing the autism specialist or I could do at that point.

Given the sense of futility in situations like that, combined with the difficulty of supporting your child(ren) and the struggle to get time off to attend all the meetings, it is obvious why some parents just stop attending those meetings. It has nothing to do with whether they care about their children.

Some people like to say that parents of disabled children are “saints” and that we will have “many jewels in our crown in Heaven.” Trust me—I am not a saint. I get impatient with my son and my husband just like every other parent and wife. You probably do too. I get frustrated and even mad at professionals and others if my son is not being treated fairly. I do think loving our children and dealing with their problems, combined with the frustrations of trying to get appropriate help, does help us grow more patient and tolerant.

UNDERSTANDING IS NOT EASY TO FIND

Maybe you have gone to support groups to try to get some insight and encouragement. You may be able to identify with other parents and find

a great deal of support even if your children have only one label or two that are commonly together. If your child has symptoms of several conditions or syndromes, chances are he doesn't manifest classic symptoms of anything. In that case, it is very difficult for you to explain your child to the group or for the group to offer the help it tries hard to provide. This is especially true if your child has a developmental-delay diagnosis *and* a mental-illness diagnosis. The waters get so murky, it is difficult to get support.

Wanting to be understood is a natural desire both for you and your child. Billy Ray becomes more agitated and aggressive when he is unable to communicate something he needs or wants. It is likely the same with you, except you don't show the aggression that your child does. You want your friends to understand. Realistically it is very difficult for some folks to relate to your life or your child. That does not mean you should throw away all your friends. Close friends will generally make an effort to relate to you and your child. It will take energy on both sides but can be very rewarding for your child as well as for you. Friends who are more casual sort of disappear, partially because they do not know how to relate. That can make you feel like you and your child have been rejected.

Eventually I found that it was worth putting my energy into maintaining a smaller circle of friends than to continue to try to maintain the larger circle I had before Billy Ray's situation became complex. Close friends will learn to overlook shortcomings in you and your child. It becomes more comfortable to have even one friend who listens and tries to understand than to be repeatedly trying to explain why your child just threw a trinket or spilled his milk.

Perhaps the most painful experience is when your closest friends and family are not able to understand. They might see negative behaviors or aggression toward you but cannot put themselves in your or your child's position. You may know that your child throws himself on the floor or strikes out at you because he is frustrated at trying to communicate his needs, his wishes, or his confusion about what is happening to him at that moment. Unless someone is around him a lot, your child may appear to others as a naughty child who is being spoiled by his parent.

Your family has sort of a double-bind situation. They may love your child, but they also love you and see the difficulty, even in part, that you go through. They wonder why you keep your child at home instead of in

some other appropriate placement. It has been my observation that those appropriate placements are suggested for the benefit of the family, and they are not always the best places for the child.

Recently we traveled to another part of the state and visited the home of an uncle with whom I had been very close as a young child. He is great with children and a loving man. Billy Ray refused to get out of the car, which was abnormal for him. Because I didn't know why Billy Ray was doing this, I left him in the car with my husband, Larry. Uncle Don was open about his concern that I had sacrificed so much of my life. He pointed out that I could not even relax and enjoy visiting him because I had to worry about my son and my husband outside in the car. He was not badmouthing my son, but he said, "You are my niece and I worry about you too." That hurt for several days. After much thought I realized that it is impossible for people to understand the commitment you feel and the choice you make regarding your child. The choice to keep a complex child at home is not a choice everyone would make. It is a very personal decision and difficult for others to grasp.

PUBLIC AWARENESS IS A MIXED BAG

The media presents many pictures of "special children." Most are high functioning, like Corky, a character in the long-running television series *Life Goes On*. Corky experienced Down syndrome but was able to communicate well and achieve many things. Someone like Corky is probably more the exception than the average child who experiences Down syndrome.

Media attention has brought some acceptance to developmentally disabled children. Unfortunately, children and adults who show some of the physical characteristics of more commonly known conditions such as Down syndrome are expected to be quiet and pleasant. When such a child begins to demonstrate behaviors that don't fit with the stereotypes, tolerance and acceptance may evaporate rather quickly.

Although understanding for developmentally disabled children and adults in general is improving, understanding for the more complex kids and their parents is not progressing to the same degree. Because these kids can frighten or, at the very least, disturb others with their noise and

rapid movements, there is not the same tolerance or social acceptance. The desire that complex children who have behavior issues should be kept at home or in a facility out of view of the public is often communicated subtly—or even not so subtly—to the parents.

You may pick up books that appear to have many answers for your child but little comparison to your child. Procedural and technical help from these books is nice, but unless you can see some comparison to your child, they don't help much. I recently bought a book that I thought was going to be helpful. The author had expertise and was a parent of a disabled child. However, I was disappointed to read that the author wondered what people must think when they see him and his child. He didn't mention how public scrutiny must feel to his child, nor did he give insight into his own feelings as a parent.

As I stated earlier, Billy Ray has been two types of child. He was charming and socially confident as a younger child. Now, as a young adult with more complex problems, he is not always socially acceptable. When he came to us as a toddler with a diagnosis of Down syndrome, he was the personification of cute and sweet. At age twenty-three, he still can be sweet and attractive in public. But more often he is noisy and bouncing, speaks profanity that he doesn't understand (so he uses it inappropriately), occasionally throws objects and/or will throw himself on the floor, or will refuse to leave a public place. When we went to restaurants and stores before his medication reaction, people would stare, partially because he has special needs, but mostly because he was just so cute and funny. People would give up their places in line for a table if they saw the table next to us was about to leave. The hosts would say things like, "Everyone wants to sit by Billy Ray tonight." Since his personality change, people stare with annoyance and irritation, sometimes make rude comments, and may move to another table away from us.

THE STRUGGLE FOR ACCEPTANCE

It is very difficult for other people to understand that your child may not be able to be disciplined or reasoned with. Before the medication reaction, you could reason with Billy Ray easily. He understood when he needed to be patient or if I was saying "no" to him. After he changed, I

would say “no” for some reason and he would not let it drop. I have come to realize that he is so focused on whatever his need or request is that he is no longer able to just let things go. Family, friends, and the public can observe illogical requests from him or accommodations that I make as spoiling him.

Continuing to struggle for understanding and acceptance of you and your child may prolong your frustration. One of the first things I dealt with in trying to pick myself up by the bootstraps and start again was prioritizing what was important in the grand scheme of life’s journey. Our whole lifestyle had to be reevaluated when Billy Ray changed. Rethinking how important it is or isn’t to have everyone understand can be freeing.

I needed to accept that:

- People do not always understand what day-to-day life involves for your child and for you. This means recognizing that because children often behave differently out of the security of home, it is impossible for most folks to understand.
- I must decide how important it is for someone to understand and then prioritize the energy I will put into communicating to that person. If you meet a rude person in a store or restaurant, you might decide it is not worth it and ignore that person. If the person is a medical or special-education professional, put all the energy you can into determining the best method of communicating your child to them. That way, suggestions and decisions the professional makes regarding your child’s care will be informed decisions.
- Even with professionals, I would have to try someone else if I have put a realistic effort into communicating Billy Ray to them and they can’t or won’t understand. You are your child’s most important advocate, so allow yourself to find a new professional, if necessary, who can relate to your child and to you.

TAKE CARE OF YOURSELF TOO

I have removed this section from my manuscript several times because I know how much I balked at this advice over the years. We hate to hear

that we have to take care of ourselves so we can take care of our children. Putting it into practice is hard even if we accept it in principle. The advice of Billy Ray's longtime developmental pediatrician, Dr. Mary Lynn O'Brien, was always to take care of myself too. Looking back, it is clear that it is the only advice consistently not taken.

Sometimes the person you may need the most understanding from is yourself. It is hard to allow yourself to be human. When your child is constantly illogical, extremely noisy, aggressive, and/or asking the same questions repeatedly, you may lose your patience from time to time. Generally, this can be as devastating to you as it is to your child. You just get tired of being punched or having your child scream in your ears. You expect yourself to have superior strength to accept what is intolerable to many people. Give yourself the same patience and understanding you work so hard to give your child.

When you do lose your patience, make peace quickly with your child. Tell her you are sorry that you were impatient, that you will try to be more understanding and patient in the future. Then give yourself a break. Recognize that if you are losing your cool, you need to get away from your child, even for just a few minutes. If possible, get someone to watch her for a short time and get out of the house. If you cannot get relief care, see if you can find an activity for your child such as watching a favorite movie or even taking a nap. Then treat yourself to a bubble bath, do your nails, or read a book just for you that's not about her needs. Even if she is an escape risk, you can do something for yourself while in the same room with her. Put a chair in the doorway to her room, sit down and read a book, or put your favorite CD in a personal CD player.

You want to help your child succeed. But whether it is taking care of your family, advocating for your child in school, meeting with medical personnel, or experimenting with the ideas that follow, you can do only so much. Do what you can without pushing yourself beyond your strength. If you are stressed, your child will be too. Slow progress is better for both of you.

Getting care for your child so you can go to your own medical and dental appointments is difficult, let alone finding time to go to the gym or do something else for yourself. Clothing, haircuts, and other things that you need for your own self-esteem often can take last place. They tap overly strained budgets and energy. They seem like things you can

skip. Then it catches up with you. One day you look in the mirror and wonder how you got to this point.

Personal care is a common area of misunderstanding. If you struggle to get your child ready for an event or appointment, he may be in much better condition when you arrive than you are. This was really brought home to me recently when I spoke to someone about appropriate attire for me when speaking to parent groups.

In trying to explain to my friend, who is so skilled at looking nice, I realized there was no way she could possibly understand. Unless you live it, you cannot know what it is like to fight with your child to get him ready for an outing, not sure you are going to make it at all. If your child finally cooperates, you can get him to church in his Sunday best while you have thrown jeans on and brushed your hair wet because there is no time left to dry and curl it. You either have to go that way or stay home.

I now can see that the times I have taken the best care of myself have been times that Billy Ray has done better too. Looking over old journals, I realized that when I began to pull myself out of the rut of self-neglect, things got better for my son as well. Whether it is that as a parent there was more to give when refilling my own “bucket” or that he was doing better so I had more energy for myself is not always clear. Our complex children notice what we are feeling. They may not understand why we are feeling down, but they know something is wrong. As we feel better about ourselves, it has a strong impact on how they feel too.