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The “Guilts”

Part 2

The “Guilts” – A Legacy Our Children Don’t Need

By Cathy Healy

In my work with families who have children with disabilities I have observed that parents are often so fretful. They want to do everything just right for their children. They want to be sure that every minute of their children’s day is meaningful. They don’t want one day to pass when their children haven’t acquired a new skill or they haven’t encouraged one to emerge. Parents work hard to make sure that their children eat the right foods and get enough rest. Yet, they still feel that they haven’t done enough for their children. Parents are under constant pressure to do all that they can to make sure that their children with disabilities will reach their maximum potential. With all this worry, we parents run the risk of passing down to our children a legacy they don’t need, the “guilts.”

Though we may not mean to, we as parents may diminish our children’s capacity to cope with their disabilities. “*Mom is so worried about me, I guess there is something bad about me. I might as well give up.*” There are so many opportunities for our children with disabilities to become discouraged and to stop wanting to help themselves. Yet I marvel that my son and others I know keep moving forward. Things that are hard for me to do are usually the things that I don’t like doing. So I avoid putting myself in a situation where I have to do them. Yet daily our children with disabilities have to do things that are hard for them,

and live with constant reminders that they have a disability.

The morning I decided to visit my son’s class, his friend Chelsea was delighted to see me. The classroom aide was not as enchanted because I was disrupting things. She insisted that Chelsea stop talking to me, sit down and get her work done. The aide chastised Chelsea and said in a not-too-pleasant tone, “*You know better than that, sit down and do your work.*” Though I know it was disrespectful, secretly inside, I applauded Chelsea when she turned to the aide and said, “*Get a life!*” and then sat down and resumed her work. Pretty cheeky of Chelsea to speak in that way to the adult assigned to assist her in school. Though she’s 11 years old and has Down Syndrome, Chelsea already knows when people are talking to her disability instead of to her.

*“Sometimes
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off the tee.”*

Later that day, I asked my son Michael to return the videos through the outside slot on the storefront window. I observed him struggling with the three videos, dropping them while trying to

open the slot. At the moment he figured out what he needed to do, another customer returning videos arrived at the window. The man offered to help, but Mike looked at the man and said “*That’s okay. You go ahead.*” The

man obliged. Off he went leaving Mike alone to complete his task. I was relieved that Mike was polite to the man and also proud that he did not allow a well-meaning stranger to diminish his capacity to complete his task at hand.

At a recent Challenger Baseball game I observed one of our players with severe physical challenges complaining to his father that he had trouble hitting the ball off the tee. The dad listened intently to his son and then replied, *“Well you know son, some days are like that. Sometimes it is hard to hit the ball off the tee.”*

At that moment, it occurred to me that what our kids need most from us is the acknowledgment that life doesn't always turn out the way we want it to. They do not need to see our sorrow and our aching hearts. They don't need to know that we live constantly with the

“guilts” because we want to fix every problem and when we can't we feel guilty. As parents we walk a fine line. We must be strong advocates for our children and we must encourage them to develop as best they can. But we must also provide opportunities that will help them to develop the skills they need to keep going and not give up. When I see the children who finally hit the ball off the tee, and they've had to swing ten times in order to do so, they don't feel guilty because it took them ten swings. They feel exhilarated because they are running to first base. That is the gift we need to give ourselves and our children; the allowance that it may take a few extra swings, but running to base is what its all about.



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