Protecting Siblings from the “Guilts”  
By Cathy Healy

My oldest child, a daughter, is in college now. It wasn’t too long ago, however, that I learned of a chilling incident that occurred when she was about 15 years old. We were at the grocery store and she had volunteered to divert Mike’s attention for a while so I could get the shopping done. Apparently, during their trip down the cereal aisle, playing the matching game of coupon to cereal box my daughter overheard a mother say to her own daughter, “You see what happens when teenagers have babies; they give birth to retards.” My daughter was horrified and never told me what had happened until a few years later.

One night, as the family assembled for dinner, discussion about a high school ethics class came up. One of my daughter’s classmates called another student a “stupid retard.” She turned to the boy and quietly told him that she had a brother with Down Syndrome and how offensive it was to her when people used that word. She then shared the story of the frightful woman who had made the odious remarks to her daughter. Her stunned classmate fell silent, then apologized profusely.

As she recounted the story, my daughter was calmly retelling the incident as if she were giving the weather report. “Cloudy with a chance of rain - teens giving birth to retards.” Her brothers and I were shocked. Before I had a chance to find my voice, her brothers did. They reacted with utter condemnation for the woman and the classmate. In anger, they blamed the woman and threatened violence were they to ever encounter her. They criticized the classmate and called him names, none of which I am able to print here. After the shock and anger disappeared, they jumped to the defense of their older sister and their younger brother. They praised her for her terrific response to the classmate and hugged her for her courage in the face of the woman’s stupid remarks.

As the mother, I was waiting for the opportunity to jump into the discussion and “teach” them how to get beyond these kinds of despicable events. An amazing thing happened. I never had the chance. I became an observer as they began problem solving how they could protect Mike and raise awareness in others. They never let me into the conversation. They were identifying the difficulties strangers had with Mike and the unnecessary hurt that the strangers’ words had caused. They began to put together responses to future “jerks” listing all the things that made their brother a unique and wonderful individual. They developed generic responses that could be tailored to many instances.

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with  
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“No, he’s not a retard, he’s my brother.”
“ He talks that way because it’s our secret language.”
“It’s called Down Syndrome and his name is Michael.”

Friends of mine who have a daughter with severe physical and cognitive delays are saying good-bye to their son as he goes off to college. They, like me, have had to hide the tears and act nonchalant about their child’s departure. If older siblings ever knew how much we really needed and depended on them to help us with the child with the disability they would never leave. But we are the parents, and it is up to us to pave the way for their exits, guilt free and with a light heart. We, as parents, must ensure that our other children, the ones without the disabilities, grow up strong and healthy mentally rather than overburdened, overwhelmed, or over-responsible for their siblings who have disabilities. We must help them navigate this life with a sibling who has severe needs so that they don’t end up owning the guilt.

Soon after Mike was born, a doctor helped me to understand how to deal with the older siblings. She said to me, “By the time they grow up, you want them to have the same level of involvement as if their sibling was going through a catastrophe like a divorce or something. They will be available emotionally, maybe even financially, but you don’t want them to be responsible for their sibling. That’s the kind of balance you want your kids to have.”

I’m still learning how to do this and I think back to that dinner conversation. That night, as my heart ached for them, it also swelled with pride. They had figured out how to deal with adversity. The care, concern and love they showed for each other at that moment made me understand that there are some things bigger than all of us. We cannot teach our children responses to each hurtful event or disagreeable situation that presents itself. We cannot shield them from all the harsh realities of life nor should we. What I have learned from my children about preventing the guilt in them is:

• They don’t have to cave and always accept responsibility for their sibling and his/her disability.
• They don’t have to always speak up for their sibling or carry the banner into the fight and act in heroic fashion.
• They don’t always have to have a smart retort to people’s insensitivity.
• They don’t have to love their sibling’s disability.
• There is safety in numbers and they provide a wonderful support system to each other.
• They do have to love each other enough to want to help each other figure all these things out.

Finally, and most importantly, my children have taught me that as parents we must help them to love themselves, and their own special brand of individuality. If we can do that, they will develop the courage to speak up to others and not tolerate the things they find offensive. In doing so, they will leave the guilt in the dust, far, far, behind them.

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