



Loving Those with Disabilities

"The true measure of the greatness of a society will always be in terms of how it treats its weakest members, and the authenticity of our own love will be measured by our compassion and acceptance of the disabled and the powerless."



Many of us have hidden fears and hesitations when it comes to dealing with persons with severe disabilities. Their unfamiliar gestures, behaviors, and limitations can challenge us and infringe on our comfort zones. We may be tempted to apply a different standard when we deal with them. Even very young children with disabilities may suffer discrimination through denial of care as newborns, or through abortion *in utero*.

During his presidential campaign, former Pennsylvania Senator Rick Santorum and his wife Karen were often asked by people on the campaign trail about their daughter Bella, who was born with Trisomy 18, a severe genetic defect caused by an extra chromosome. Such children tend to have shorter life spans, with 90% dying during the first year of life. Nevertheless, with proper care, some can live well into their teens, and even into their 20's or 30's. Bella became known to the public during her father's candidacy in part because of several memorable moments during the TV debates where Rick powerfully described how Bella's birth and struggles had impacted their family.

Early on, Rick and Karen struggled with the Trisomy 18 diagnosis, and with the way physicians labeled it a "lethal diagnosis" and

"incompatible with life." Because they had already lost another child at birth, Rick, almost without being fully aware of it, remained emotionally distant from Bella during the first few months of her life. He focused on being the pillar of strength for the family through the storm. He later described it during one of the public presidential debates this way: "I decided that the best thing I could do was to treat her differently and not love her... because it wouldn't hurt as much if I lost her."

Several years prior to Bella's birth, Rick had sponsored the partial-birth abortion ban in Congress. He had spent long hours on the Senate floor lobbying to protect children who were discovered to have "problems" before birth, rather than allowing them to be targeted for late-term abortions.

When Bella was 5 months old, she became critically ill and was rushed to the emergency room. Rick grasped her little finger on the gurney where she was lying.

"I remember holding that finger," he said, "and looking at her, and realizing what I had done. I had been ex-

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actly what I had said that I had fought against at the partial birth abortion [hearings]: I had seen her as less of a person because of her disability.”

His candor is a reminder of the challenges we all face in caring for and loving those with disabilities and physical limitations. Having learned many valuable lessons from their daughter, Rick and Karen now serve as even more vigorous advocates for children with disabilities. They realized they had to immerse themselves in the world of special needs, which Rick described as “a different world,” and one where children like Bella “do not get the care they need unless the parents fight for it.”

I recently had the opportunity to meet Rick and Karen. Karen described how Bella’s situation was exacerbated by health care professionals who would not treat her with the same dignity and respect as normal children. Surprisingly, some doctors did not even address Bella by her name. Rick and Karen soon found an exceptional team of physicians who not only called Bella by her name, but were hopeful and positive about her life and possibilities.

Karen also mentioned another

couple with a child affected by Trisomy 18. They had been told after delivery that little could be done for their newborn, and the child was placed off to the side, until one of the parents noticed her struggling and sought assistance for her. Other parents spoke to Karen about the subtle but noticeable resistance among medical staff whenever they brought their child with Trisomy 18 to the hospital for medical attention. The Santorums had experienced similar challenges with caregivers and medical staff. They had to fight to get the prescription for oxygen, and basic medical supplies, that Bella needed after she left the hospital; in addition, a hospice physician prescribed what would have likely been, if administered, a lethal dose of morphine.

Discrimination against those with disabilities should never be allowed to gain a foothold in the medical profession, nor be allowed to guide public policy. The true measure of the greatness of a society will always be in terms of how it treats its weakest members, and the authenticity of our own love will be measured by our compassion and acceptance of the disabled and the powerless. God seems to send us children with disabilities to help us grow, to remind us

that every soul is of greater importance than its frail body, and to teach us how man’s highest calling is found in his God-like possibility of sharing unconditional love.

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