



By Caryn Sullivan

AUTISM, CHURCH AND RESPECT FOR THE SOCIAL CONTRACT

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I've been following, with much dismay, the media reports and Internet blogging about the parents from Bertha, Minnesota, who were repeatedly asked, then finally ordered, by the court, not to bring their son with Autism Spectrum Disorder (ASD) to St. Joseph's Church. According to documents filed by the church in support of the restraining order, 13-year-old Adam Race's behavior had become "extremely disruptive and dangerous." The church alleged, among other things, that while in church Adam had nearly injured children and elderly people and that his parents used physical restraints on him. Adam's mother, Carol Race, violated the order on Mother's Day by taking all her children to church while her husband remained at home. She was later charged with a misdemeanor and now says she feels she's being treated like a criminal.

Local and national media have reported on Race's position that they've attended the church for years, that her son is neither angry nor violent and that the church has not fulfilled her requests for accommodations (although it's unclear what accommodations she's seeking). Race told a WCCO reporter that she sees herself as Moses leading the parents of autistic children. She also said she is in a battle to protect the rights of severely autistic children and to make churches aware of the needs of special-needs children.

I've spoken with many who, knowing that I am a Catholic mother of a teenage son with ASD, have asked, "What do you think about this story?" Frankly, I think it's a hornet's nest that I'd prefer to stay out of. But I'm so troubled by it that I can't remain silent.

Although I empathize with Race, as one mother to another, I don't believe this case involves discrimination against a person with ASD. Moreover, I'm deeply concerned that framing her crusade that way has served to further polarize people within and outside of the autism world. Most of all, I'm unhappy that someone whose situation is so different from mine has declared herself the leader of people like me.

I don't think the church responded the way it did because Adam has autism. I think that the response had to do with extreme behaviors that were understandably worrisome to both the church leaders and parishioners. I think this controversy could just as easily arise if a parent of a hyperactive toddler or a child with schizophrenia who lacked adequate social awareness or self control took her child to church.

Nor do I believe that the church has taken an unreasonable position. It must balance the needs of all parishioners who gather for a peaceful mass. While Race may have had difficulty with her place of worship, many families like ours have not, perhaps because we've kept our child at home when we felt he could not behave properly at church. In my view, this dispute highlights the heartbreaking challenges that parents face in determining how and under what circumstances it's possible to successfully integrate a child with ASD into society, particularly one who is severely challenged. I don't think that

these issues will be resolved through political activism or criminal prosecution. Successful resolution requires more education of the public, acceptance of reality by families, and potentially uncomfortable discussions.

Increasingly more people with disabilities — not just ASD — are being mainstreamed into our society, rather than being secluded in institutions, as in years past. They are integrating into our school systems and transitioning into the work force. They are recreating, socializing and living in our midst, attending churches, synagogues and mosques. Parents and professionals are working to position them for success but there must be a give and take between those who are challenged by a disability and those who are not. It will require both sacrifice and tolerance.

There is a social contract that requires all citizens to act reasonably and respectfully toward one another. Sometimes, abiding by that contract requires us to make tough choices that we'd rather not make.

I can understand how for those who know little or nothing about autism, seeing 6'2" 225 lb. Adam Race sitting in the back pew of the church in his urine-soaked pants with his hands or ankles restrained to calm him would be not only distracting but deeply disturbing. I'm concerned that when people hear "autism," this is the image that will come to mind.

Although our son is verbal and not violent, he doesn't always do well in social situations. We've used a cost/benefit analysis many times, evaluating the stress on our son and our entire family if he were to attend church, siblings' confirmations and graduations, family vacations, and much more, always mindful of how his behaviors might affect others. It's not been easy, but we've gone without him on many occasions.

Autism has no corner on that market, though. A friend shared with me that her mother-in-law, a lifelong churchgoer, stopped attending church because in her advanced-stage Alzheimer's she has such horrible, uncontrollable flatulence that she was disturbing folks three pews away. This family made a tough decision to keep her home — out of consideration for both her and others.

I'm confident that there are many people with ASD attending churches across the state today, just as there are people with ASD who stayed home because it would be too hard for them to sit through an hour long church service. Maybe that means parents attend church separately. Or maybe the child goes into a special room at the church or celebrates mass at home. Sacrifice and compromise. It's tough but it's our reality.

I do agree with Race that awareness about autism is necessary and important. To that end, I've written on these pages about my experiences with my son, hoping that by doing so I would increase awareness and compassion. Readers have responded with appreciation and encouragement, reinforcing my view that people are fundamentally reasonable and kind but understandably wary of things they don't understand.

Now that she has national attention focused on the controversy, I'm frankly not sure what Carol Race hopes to accomplish. If her goal is to return to St. Joseph's, then I hope she will negotiate with the parish to resolve this matter quickly, following the model of sacrifice and tolerance. If her goal is to increase awareness, then maybe she should pull back the curtain on her family's life and help neighbors and parishioners to understand Adam's needs, challenges, and strengths, and the strategies they use to address them.

Since I've jumped into the hornet's nest, I may as well ask, mother to mother, the question many have posed to me. Carol, what exactly is your end game? Is it to raise awareness or to raise Cain?

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