

WHO'S THE
Slow Learner?

A Chronicle of
INCLUSION & EXCLUSION

SANDRA ASSIMOTOS MCELWEE

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A Chronicle of Inclusion and Exclusion
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Dedication

This book is dedicated to my amazing husband Rick. You were my balance in all the times I became unbalanced. You are my rock every time I want to crumble. You are on every page of this book as you allowed me to disappear to write, and endured the piles of papers as I reviewed old IEPs and communication notebooks. You never discouraged me from this endeavor or any other I have dreamed up. The best father Sean could have, patient beyond imagination as you coach him and his friends in multiple sports. I Love you.

*In Memory of
Shelley Green
Jonathan Riggs*

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DEFINE the word *educator* and you all should be teaching and mentoring other teachers in the true meaning of the word *teacher*. To the fifth grade teacher—you got to know Sean better than most—your sense of humor and calling to be a teacher is a gift to all your students and their parents. To the classroom assistants, the third Independence Facilitator in Intermediate school and Sean’s aide in high school—you ladies were the glue to bring all of the preparation together. Sean loved you all, and I appreciate the stealth code you used in his communication notebook to let me know when things weren’t quite right. To the district inclusion specialist and inclusion facilitator – your imagination and support made the journey easier. I know how hard it was to sit and watch while your hands were tied while Sean was being discriminated against. To the high school case carrier that believed in Sean and advocated for him; thank you for always doing your best to provide opportunities for growth. Thanks go to the high school Special Day Class teacher who allowed Sean to join her class one period a day for work experience. And to the Varsity Baseball Coach who embraced Sean as a team assistant; I pray you advocate for your son and make sure he has at least as many experiences as Sean has enjoyed. To the high school principal, I am sorry you got caught in the cross-fire.

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Foreword

As parents of a son with Down syndrome, Stephen (4 years older than Sean), we read this book with great interest. *So Who's the Slow Learner?* is a chronicle of a mother's journey to bring out the best in her child with special needs, while surviving and thriving herself. Sandra reveals the joys, sorrows, rewards, failures, and the daily challenges of raising and educating a challenging child.

From infancy through adolescence, Sandra explains, often in graphic detail, how she used a mother's determination to advocate for the best available resources to help her son navigate a not-always-friendly educational system.

By reading this book and often identifying with the author, you will also learn how to use educational and occupational resources in your community that best fit the special needs of your child. Of course, every child is not like the star of this book, nor can every parent do what this mother did. Glean from this story what fits your child and your family. As you read, some pages will make you smile; others will prompt anger and sadness. Our hope is that this very personal account will encourage you to be a wiser and more informed advocate for your child.

William Sears, MD, and Martha Sears, RN
Authors of *The Successful Child: What Parents Can Do to Help Kids Turn Out Well*

Foreword

Sandra McElwee is a true testament to my favorite quote by Martin Luther King, Jr.: “Cowardice asks the question, is it safe? Expediency asks, is it polite? Vanity asks, is it popular? But conscience asks the question, is it right? And there comes a time when one must take a position that is neither safe, nor polite, nor popular—but one must take it because it’s right.” When a mother gives birth to a baby, there is much cause for celebration, for great anticipation, for sheer exaltation. Instead, mothers of children with Down syndrome are often presented with sheer dread, fear of the disappointments and hurdles ahead. Why? Because most, if not all, of the professionals—the doctors, nurses, genetic counselors, ultrasound technicians, etc.—never had the chance in their life to get to be friends with a guy like Sean. Sean was, and continues to be, vital to our human race. He has, and must continue, to teach us how to value and respect diversity. As a species, we are bland, monotonous, insipid, banal, and lifeless without him. Our humanity is continued to be denied the vibrancy, texture, and opportunities afforded it because of disability bigotry; because so much of society is afraid and ignorant. Whenever we have the conversation about inclusion we always hark back to civil rights issues.

Another favorite quote helps elucidate this conundrum: “Nothing in the world is more dangerous than sincere ignorance and conscientious stupidity.” People of various cultural and racial backgrounds are unfamiliar and therefore feared. Even still, racial, ethnic, and

gender diversity, no matter how unfamiliar, is now protected by law and little, if any, segregation is legally abided or supported. The only marginalized segment of our population in this country for which segregation is not only permitted but encouraged is that of individuals with disabilities.

Sandra McElwee chose to take a path for Sean that was neither safe, nor polite, nor popular, but was right. Moreover, when Sandra took the right path, Sean benefitted from an inclusive education that most likely led him to tolerate and succeed in spite of the period of time in which he was segregated. Although his environment made him more disabled during his time in his segregated day class, he managed to overcome those obstacles, against all odds; to rise up from the ashes of exclusion like the powerful phoenix that he is, and look forward to a future of integration with a quality of life befitting any valued, respected, worthy human being on earth.

Jan S. Weiner, Ph.D.

Introduction

Only God can turn a mess into a message, a test into a testimony, a trial into a triumph, and victim into a victory. God is Good All the Time!—Rick Warren

I was once asked why I write, and my answer was, “To educate and inspire.” God gave me a son who is an inspiration. Sean was born with Down syndrome and has been a blessing from day one. He has a great sense of humor and loves people, especially girls. In this book, I chronicle his education experience, which is mostly cataloging the reactions he engenders as he finds his place in this world. Since birth, Sean has had a magnetic personality and draws amazing people toward him, and like a magnet, he is also a force to be reckoned with. He repels people who are narrow and prejudiced. Sean is very strong willed and determined, which serves him well when he is working to achieve a goal. He is also impulsive. He inherited his father’s fantastic sense of humor, good looks, and athletic ability, and from me, his determination, drive, and outgoing personality . . . and inability to accept “No” as the answer to any question.

My goals for writing this book are to chronicle my son’s educational experiences, and the education I subsequently received in the process. This is not a “How-to” book, but a “How we did it” book. This compilation of stories contrasts the good and the bad, the funny and the sad, the great character and poor character of the educators Sean encountered in his years of public schooling. I have interspersed

stories of Sean’s life experiences—they are mostly chronological—but some cover the span of many years. My hope is that parents will understand the challenges, learn the educational rights their children have, and recognize that ability does not dictate whether a student can be fully included in regular education classes or not.

I have included Sean’s IEP (Individualized Education Plan) goals for each school year. I did this to demonstrate that Sean was not on track with his regular education peers, but he did make progress and learned much more than he would have had the opportunity to learn in a special education classroom. I have only listed the crux of the goal. Each goal is actually written beginning with the area of need being met, a baseline goal, then measurable goals gradually increasing over three assessment periods. The goals always end with language like, “with 80 percent accuracy in two of three trials as measured by observation and data collection.” Most of the goals after seventh grade were poorly written and don’t deserve to take up more paper on this earth.

Sean once told me he wanted to be a teacher. I responded, “You already are a teacher.” Sean teaches people patience, tolerance, careful listening, creativity, and compassion. As for those who don’t want to learn from him, he teaches me about their character if they openly reject his presence with bigoted words and actions. I particularly appreciate that lesson so I don’t have to waste my time on them.

The idea for this book began when Sean was in seventh grade, and the IEP team at his intermediate school was displaying some extremely slow learning and bad behavior when they were working overtime to exclude him from regular education. I realized I had a lot more material from all of Sean’s life—and many situations where I was the slow learner in relation to Sean!

At first, I really hesitated, because some of these stories could be construed as negative, and some of the character flaws of the educators could really be depressing. But there *is* humor in every situation, and there is hope, and there is an opportunity for the educators to learn what *not* to do from this documentary of human flaws. Also,

parents can learn to be aware of the hidden meaning of subtle, and not so subtle, phrases made by *the professionals* and know to ask more clarifying questions to make sure they fully understand the implications of recommendations made by educators.

Another lesson I hope readers take away is that we do not need to be offended when people say and do cruel and ignorant things. Rather, we can take those situations to teach them the error of their ways and hope to open their minds in kind response. Don't deflate. Educate! It can be so easy to crumble when conflict occurs, but remember, everything you do is for the benefit of your child. Most of the educators are only temporary figures as your child moves through the educational system. But these educators will have the experience of working with you which can positively impact their interactions with other students with diverse learning needs in the future. We have a great opportunity to leave the world a better place!

I once asked a district-level special education administrator why I didn't experience the negative situations that many parents were telling me they were experiencing (this was before seventh grade). She responded, "When somebody has a concern about Sean, you listen and work *WITH* them to solve the issue at hand. Most other parents take offense to everything and feel like they have to *defend* their children's poor choices instead of working *with* everybody to create a different outcome."

We, as parents, can make things harder for our kids when we micromanage every aspect of our child's education and don't agree with every little action of the educators. This can be so annoying to the point people make rules to exclude our children because of *us*. When there is something you feel needs to be changed, there are ways of doing it. Thankfully, the parents who walked this path before us advocated effectively and now we have the Americans with Disabilities Act (ADA) and the Individuals with Disabilities Education Act (IDEA). Even the United States Department of Education's Office of Civil Rights provides the legal basis to support us and our children. But even when we have the law behind us, do not expect that

educators and others will *know* the law. We may have to respectfully educate them on the law. But if they continue to ignore us, then there are ways to respond with Compliance Complaints and Civil Rights Complaints.

One big lesson I have learned is you can legislate rights, but you can't legislate attitudes. While it is our children's right to be included in a regular education class, if the educator is so fearful and set against including our children, then I have learned it is better to not force the issue with that particular teacher. The outrageous behavior some educators exhibited toward Sean were not worth the mental anguish that he experienced being in their presence.

Also, do not get overwhelmed by reading this book. I have the great ability to quickly overwhelm, and I want you to know, Sean is my only child, I have a ton of energy, and an incredible husband that is on the same page as I am on everything. I know when you are on your own, or you don't share the same philosophies with your spouse, everything becomes harder. You aren't just battling the *system*, but the battles can start at home—and home should always be a place of refuge and comfort, not strife and contention.

Every obstacle can be viewed as an opportunity or a stumbling block—and I see this as an opportunity to learn and be aware of some outdated or prejudicial ideas that people may still have. And I pray you never encounter any of the negatives, but can savor the positives and recognize when all is awesome . . . How sweet it is!

IF You Are Married

It is critical that both parents be on the same page in philosophy and beliefs. It is very easy for the educators to *divide and conquer* when it comes to educational decisions, and be very careful you don't *divide* to the point of a permanent marital divide. They particularly will use this tactic when a divorce is already present. Remember Hillary Clinton's famous line, "It takes a village"? Well, it certainly does. Seek support from parents who have traveled this path. Discuss what your plans are before IEP meetings and know that decisions do

not have to be made on the spot. It is acceptable to schedule another meeting and allow yourself time to discuss matters in private and research answers outside of the meetings. Make huge attempts to not disagree in front of the educators (or your children). This chink in the marital armor is all some need to move their agenda forward. Nurture your relationships. Untended fires soon become a pile of ashes.

For Teachers

This is Sean's story; a story of how his inclusion was done right, and how his exclusion was done wrong—not a “how to” book. This is from my perspective, and as an educator, you may not agree with many of my observations and opinions.

One thing you need to know about people with Down syndrome. They may not be able to tell you what they are feeling and thinking. But please know that they *CAN* tell what *YOU* are thinking and feeling. And they will react to your feelings in kind if you are kind, and with unbelievable acting out if they know you don't want them or accept them. There's a sixth sense on who is an angel and who is an avoider implanted in the twenty-first chromosome. People with Down syndrome also have incredible memories and won't forget what negative things have happened to them and will remember something that happened in the past and react as though it happened just this moment and you won't know why they, all of a sudden, are angry or upset. You may think it's because of something that just happened when, really, it happened a month ago. They remembered it, and had the same emotional response as they did when it actually happened.

The question is—will you *ENDURE* having a student with a disability in your class? OR, will you *EMBRACE* the opportunity to grow and learn? What you learn about teaching a student with a disability will help you teach all of your students. All of your students will benefit by learning acceptance, respect, and to value and be unafraid of people with disabilities. Your students are the future teachers, co-workers, managers, physicians, parents, and, hopefully, friends of people with disabilities. Simply being in class with children who are

differently abled may inspire their future more than you can know. Will you step up to the challenge of inclusion? Will you step out of the box and grow and allow *ALL* of your students the benefits of inclusion?

To the teachers who got it right: You are the wind beneath my wings. As my inspiration, you gave me the strength to keep going when the going got tough later on. I wish all children could have teachers as amazing as you are. You accepted Sean even though he acted unacceptable many times. And I truly appreciate how you worked with me in problem solving and didn't discount any suggestions that I had.