

*Marilyn Dolmage speaks up on Ian Brown's Globe and Mail Articles.*

*Check it out.*

On three successive Saturdays, the Toronto Globe and Mail published lengthy articles by Ian Brown, a writer and father of a son with significant disabilities. Marilyn Dolmage is a mother and advocate. Her son Matthew who lived with significant disabilities passed away in 2004 at age 29. In the commentary below she presents a very different perspective to the one Ian Brown voices in the Globe and Mail articles.

**Read Marilyn's commentary and let us know what you have to say by connecting to our feedback page.**

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*Below is a personal response I have written to the recent series of articles in the Globe and Mail by Ian Brown, about his son Walker.*

*This gave Brown arguably the largest public platform anyone has ever had in this country about issues of disability. I have anguished about what he wrote - which I found extremely demeaning of his son. Many people seem to admire Brown's "honesty", but I have reason to believe he has crafted a very devious story indeed. I can understand why he is stuck, but I cannot condone the position he takes.*

*I don't really think Ian Brown will listen to us, nor is he interested in learning from the lives of the people we love (except perhaps as curiosities, as objects for his research). But I think others will. And I am appalled that there is so little response challenging Brown's perspective.*

*My comments are too long for the reader response format the Globe has set up - which today contains what I consider to be a very limited reply from L'Arche Canada to Brown's misrepresentation of Jean Vanier's ideas about inclusion and belonging. But I will ask the Globe and Mail to print what I have written as an OpEd piece, nonetheless.*

*I have also emailed my comments to Nancy Evans (at Environics Communications [nevans@environicspr.com](mailto:nevans@environicspr.com) 416-969-2704) who is a contact person on a press release about the Globe and Mail series.*

*My main reason for writing this response is to encourage the people with disabilities and families alongside whom I work. I don't want anyone to think that Ian Brown has all the answers, or even that he is asking the right questions. I don't want people to think I would fail to defend our values, our work, our whole way of life. I hope that you will share what I have written with anyone else who might need some encouragement. Even small steps away from segregation lead to a better life, when taken with conviction and respect.*

*I hope that you will write about what this means to you and why it is so important.*

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In the film *Mr. Holland's Opus*, we are fascinated to watch the avid musician and much-loved music teacher struggle as father of a deaf son. In our town of Gravenhurst, Ontario almost 34 years ago, people wondered how a high school phys ed teacher and revered sports coach would respond to his infant son, who was so challenged physically, medically and developmentally. Globe and Mail readers across Canada have been intrigued to read a brilliant, articulate journalist's story of his struggles with his son who has significant cognitive and communication disabilities. We are told not to look at people who are different. Maybe that makes us feel especially the shock, the pathos when we get the chance to learn about people whose challenges seem greater than our own. When we look, what do we see? Do we really understand? Then what will we do?

Parenting is difficult, even overwhelming at times in its assault on how we live and how we feel about ourselves. Desmond Morris said human babies learn to smile because they need to reward their "naked ape" parents, lest they abandon them. Expectant parents hope their child inherits all the characteristics they like most about themselves. When a child has congenital disabilities, parents receive information about life-altering deficiencies. This child's life might never be all the parent hoped it would (as if it ever is). But the parent's self-image is challenged too. If we have always distanced ourselves from people with disabilities, we don't know what to do. This makes parents especially vulnerable to the medical experts and therapists we meet, who frame both the problems and the ways we address them. Sometimes those professionals demonstrate their own frustrations, biases and fears. When our child has genetic differences, we are taught that everything about him or her is flawed. And then we are suddenly alone with a baby who needs us so much, who doesn't flatter us, for whom we feel so unprepared.

Ian Brown has had pages and pages of newspaper exposure, perhaps the biggest public spreads and centrefolds ever – to display his struggles as fearful and frustrated father of Walker, now aged 11. This gives him such power to tell that story as he wishes and to be seen to represent other families of children with disabilities. Globe and Mail respondents have conveyed their fascination (finally a chance to stare), their awe (about what seems so awful), and their relief (thank God it's not me). Brown uses clever metaphors to describe his son as so unusual and defective; his behaviour so terrible and troubling. Walker is called a mutation and his world is so alien that his dad calls him "the boy in the moon" and concludes there's really no one there. The father is in our faces with stark detail, ... , politically incorrect admissions and bold machismo, while the son still seems

so distant. Brown begs us to care about Walker's future but, on the Globe website, some readers have suggested even greater distance –more group homes, even euthanasia.

My life has brought me up close to people with disabilities, their families and society's responses. I was 4 when my brother Robert was born, but I only saw him once, after he died. Because he was seen to have Down Syndrome, he was sent to an institution at birth, never touched by anyone who loved him. I grew up staring, wondering how things could be better than that. I became a social worker in that institution, convinced I could not do its "front line work" (what an image) and sure that families like mine needed help. As fate would have it, my first child Matthew was born with much more daunting challenges than my brother's (that Gravenhurst phys ed teacher I mentioned above is my husband Jim). Like Ian Brown, we were told that our son's problems were genetic, greater than any other child's and particularly trying for professionals. So we found ways to get our son – and especially ourselves - out from under such influences. It's encouraging that Brown says of Walker's older sister Hayley: "she alone took him in her stride". Our younger children Leah and Jay showed us a new world of difference – by living so intimately with their older brother and admiring Matt for himself. Like Walker, Matthew experienced segregated school. But when he demonstrated self-injury and frustration there, we moved to a community where Matthew became a member of a regular classroom and our children could attend neighbourhood school together. We all thrived when Matthew was treated with respect as a unique individual and was seen for his strengths, particularly in music. Even without words, he communicated brilliantly. We had no nanny; we wanted no private, for-profit group home (costing taxpayers \$250 a day). Instead, we worked with other families to obtain Special Services at Home funds and then Individualized Funding. The whole family was stronger because we accessed a relatively small amount of government money to hire people who supported Matthew's choices – from attending Beavers and Cubs, to volunteering and part-time work after he finished high school. I once read that the kind of problems Ian Brown portrays will never be resolved by old minds with new programs, but by new minds with no programs. Matthew had lived in Toronto for just over 2 years, when he died suddenly in 2004, at the age of 29; yet he was honoured for his contributions by the Mayor and City Council. Many people shared his life, and share our loss.

Ian Brown wrote disparagingly about "integration", calling it "the current educational orthodoxy that the handicapped should live within the normal community, as pretend normals". For such a clever journalist, he is so misinformed. Since before Walker Brown was even born, people across the world have been working – no longer at "integration" but for "inclusion" - towards a world where all differences will be truly welcomed, equitably accommodated, and really celebrated. Are we there yet? No, but no one should dismiss the efforts of the families working very hard for change, every day and every night.

Of course, Brown set up his story to negate the stories of people like me. He will say Walker is more disabled than Matthew was. He will say that families like mine are delusional – maybe it's the stress. I am so sorry it's too late for him to meet Matthew, but I can introduce him to many other people who are part of rich and diverse communities. Their stories may never be as available to Canadian newspaper readers, but their neighbours know and admire them, and their families are not alone. That can make all the difference.