

## **SOME REFLECTIONS ON .... LIFE, MY FAMILY AND INCLUSION**

**BY ANNE KRESTA, Parent, Winnipeg**

All of my life, I have had a passion to support the underdog...not out of a sense of cheering on the little guy, but of ensuring that we all enjoy the same rights and freedoms and opportunities for full citizenship in society. This may have come from being raised in a family of five children, each with their unique gifts and challenges, and one of whom was born with an intellectual disability (I call her my little, big sister as she is much smaller but older than I). And then, low and behold, of my three children, the older two were born with neuro-developmental disorders that included Asperger Syndrome, non-verbal learning disabilities, Tourette's Syndrome, Attention Deficit Disorder and assorted other challenges.



Early on, my family was challenged by a school system that did not know what these disorders were and were at a loss when it came to how to appropriately support our sons. This, while we still held fast to the belief that if our sons were going to be able to become contributing citizens in their society, they needed to be included with their peers in an inclusive education system that could offer high quality education to all of their students.



When our initial fight for appropriate supports began 15 years ago, we faced a system that had no mandate to provide appropriate education to our children. In Manitoba, legislation mandating appropriate educational programming only came into effect in 2005. We were faced

with “well-meaning” teachers who blamed our parenting for the perceived shortcomings of our children...if we only tried harder to be consistent in our discipline, our sons would have been so much better off!

We had to attend countless meetings with countless professionals and still we were not able to garner the support that was needed. Being unfamiliar with the inner workings of the school

system, we did not know how to proceed through the appropriate channels to bring our concerns forward. **But we learned quickly!**

**“Private words”** (in back rooms, away from other ears and eyes) with assorted personnel helped us to determine how funding applications worked. We learned how to launch appeals of funding decisions. Ultimately, we learned how to portray our sons in their **worst light** on the day of the site visit by the “powers that be” (Department of Education personnel).

Since we concluded that this battle could not be confined to our family, we began to reach out and look for other parents. The community living movement came into our lives at that point, not because our sons necessarily met the mandate of the organization, they do not have intellectual disabilities, but because the fight for inclusion is our fight together. There was strength in numbers and in sharing the experiences that the organization had had in working towards the community inclusion of people with intellectual disabilities since the 1950’s. We were strengthened by our association with Community Living Manitoba and the Canadian Association for Community Living. We learned from other families and became much more effective in promoting our message.

Our sons did get the support that they needed so they could get an appropriate education. We still had to work with each of the successive schools that they attended to ensure that their “appropriate” education was inclusive. There are still segregated programming options out there. We had to be firm in our resolve that our boys would be included. We believed they should have support to be in the regular classroom with their peers with teachers who knew and supported them.

Early on, this work was almost a fulltime job for me. I attended numerous meetings and I was “on call” every day. I was expected to coaching the school staff through challenging situations. I provided “down time” to my sons as they dealt with the sensory overload that comes from being integrated into a regular classroom setting.

Happily, as they matured, the boys learned to understand their own triggers. They learned to take five minute breaks from classroom activities. They have learned to cope on their own and the school personnel are able to work more effectively with them. And we even reached the point where teachers worked with our sons not because they have to, but because they want to. Our sons are valued members of their classrooms.

It is gratifying to see how the inclusive education - appropriately supported - that my sons have been experiencing is paying off! We can now see possibilities in their future we didn’t see before:

- for employment,
- for community participation,
- for their contributions to the world; and

- for society's acceptance of them for who they are.

That being said, in the work that I do with Community Living Manitoba, as the Inclusive Education and Community Development Specialist, I too often hear stories that are similar to my own. I hear how parents are still required to demonize their children in order to gain appropriate supports. I hear how teachers still blame parenting for the child's behaviour at school. I learn how parents still do not know the appropriate processes to follow when trying to secure what their children are entitled to now that we do have legislation in Manitoba.

Another frustration in Manitoba is each of the many school divisions sets their own policy regarding how children with disabilities are supported. They even differ in how funding is granted to a child and how it can be used in the school. We have schools and school divisions who "get it" and really are champions of inclusive education. They see the benefit, socially and academically of having children of varying abilities within the classroom with supportive and supported staff.

Other school divisions and even schools within some of the better school divisions seem to be more "old school" with attitudes that stem from older teaching practices. These divisions and schools may go through the motions of providing appropriate education (scheduling meetings, inviting all of the specialists, creating individual education plans, etc), **but their hearts are not in it! And it shows!**

The result is unmet IEP goals, disenchanting parents and professionals, and ultimately, students who are alienated from their peers and don't receive the education that they need.

It is encouraging to see more and more teachers coming out to training opportunities that provide them with the tools they need to make inclusive education work. It is also encouraging to see so many resource teachers becoming school administrators, bringing their vision of inclusive education to life within their schools. More students are succeeding in the school and going on to better opportunities in their post-secondary lives. More parents are feeling supported by the school system. They are all partners and collaborators in planning for their children's membership in the school community.

As we move forward with the inclusive education agenda, we need to safeguard against those who want to provide "**specialized opportunities**" for our children in segregated settings, whatever the reason. We need to share our stories about the benefits of inclusive education, not just to students with disabilities, but also to students who do not have disabilities. Public education should be about educating for citizenship, for belonging, for democracy, and this cannot happen without inclusion in the classroom. Our teachers and education system need our support. Our politicians need to hear from us that this is the right thing to do.

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