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*PARENTS WITHOUT PREJUDICE*

*BY Gregor Wolbring*

THE FOLLOWING QUOTATION about thalidomide children and their families is from *Dark Remedy: The Impact of Thalidomide* written by T. Stephens and R. Brynner (Perseus Publishing, 2001). This quotation illustrates the attitudes of society that my parents and I faced.

How did parents endure the shock [the birth of a thalidomide baby]? The few who made it through without enormous collateral damage to their lives had to summon up the same enormous reserves of courage and devotion that are necessary to all parents of children with special needs and disabilities; then, perhaps, they needed still more courage, because of the special, peculiar horror that the sight of their children produced in even the most compassionate. Society does not reward such courage... because those parents experience represents our own worst nightmare, ever since we first imagined becoming parents ourselves. The impact upon the brothers and sisters of the newborn was no less horrific. This was the defining ordeal of their family life –leaving aside for now the crushing burden on their financial resources from now on”. (pages 65/66)

Public perception was that parents of thalidomiders had it very hard because their kids were indeed seen as monsters. In some way, this reaction was understandable as the visible physical differences were similar to people coming back from wars without legs or arms. And, society's views about war and war veterans have often been quite negative. In addition, there is a basic societal understanding about how humans perform everyday tasks using their arms and legs. As a result, it remains difficult for people to accept individuals who eat with their feet and use crawling, rather than walking, to get around. People are expected to walk on their own two feet. It is not surprising that public discussion of selective abortion and euthanasia/mercy killing surged after the publicity that followed the birth of thalidomide babies. At that time, it was commonly believed that thalidomiders were better off dead because they were suffering a great deal and would never be able to enjoy life.

My parents encountered these prejudices by neighbours and relatives as well as society at large. And, being brought up within society, many parents of thalidomiders were prone to feel the same prejudices themselves.

But I was lucky. My parents never had such prejudices. They accepted me as I was. Despite my look and the inability to look back in history and see what people like me could achieve my parents accepted me – even through the difficult experiences they had with me during my hospitalization as an infant and young child.

Furthermore, my parents were strong enough to reject modifications to my body proposed by the medical professions, such as cutting off my feet, which would be irreversible and seem to serve no purpose. They did accept artificial legs for me –which they saw as useful. However they did not stand in the way when I decided, later on in life, that I'd rather not use them. This was made possible by the fact that these legs were add-ons, which could be removed easily.

My parents were not rich or otherwise special, except that they were without prejudice and did not impose certain expectations onto their kids. They also did not expect their children to be tools to serve their desires and needs.

Thanks to their love and acceptance, I developed high self esteem and was able to become comfortable with my nonmainstream body and with who I am. I was able to develop my movements and other adaptations I felt were useful for me. I never felt ashamed about crawling. For me, it was and still is my natural way of moving.

With my self-esteem, I was able to take on the bullies of the world and disregard them for what they are. I never felt I had to prove myself to them and I never saw myself as defective. My parents always helped me to look at the bigger picture. They made me aware that I was not the only one bullies would target. They enabled me to cope with the bad treatment I sometimes received.

My self-esteem has come in handy in many stages of life. Without my high self esteem, I would have never tried to become a biochemist or ventured into disability politics to try to help other people with disabilities and their relatives and friends. Professionally, I would not be fighting for a disability rights approach within the field of bioethics.

When I was fourteen, the school in my hometown was moved into a wheelchair inaccessible new building. When this happened, my parents and I decided to find an accessible mainstream school. But, the one found was too far away from home for a daily commute. As a result, each night, I stayed at an institution for people with disabilities in the same town as the mainstream school. – until I was twenty. At the institution, the residents were treated as defective people and expected to be thankful for everything that was done for them. Without my self-esteem I would not have survived that institution and been prepared to confront the prejudices of the world.

My self-esteem had evolved during my first fourteen years with my parents. I had learned that I had rights as a person and that I was not defective. I also learned two important

perspectives from my parents: to not get hung up on people who treated me badly, or take such treatment personally; and, to focus on those individuals who were kind nice friends. Living by this outlook themselves, my parents were able to ignore the prejudiced people and to enjoy their many friends and relatives. And, the majority of my parents' friends and relatives accepted me as I am.

As I grew older, I developed my own relationships with some of my parents' friends. Friendship is important to me. I am still in contact with people from elementary school and from other times when I developed the friendships.

My parents also taught me the responsibility to do my share against prejudice. If they hadn't seen past public perception and prejudice, I wouldn't be where I am today. I now appreciate how lucky I was to have been raised by my parents.

To bring the story full circle and in contradiction to the quote with which I started this essay, I was never the monster and I did not destroy the lives of my parents or younger sister. Society was, and often still is, the monster. Society's unwillingness to accept and support the diversity of human beings is the major threat to the well being of people with disabilities and their families Children and adults with disabilities are not the threats. My parents are not worse off because of me. In fact, they have said, that I helped them have a better live because they focused on the key issues in life -- friends, acceptance and being human.