
*By Dale Tassi, Social Worker*

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I really enjoyed this book, especially chapter 3 written by Stephen Shore entitled “Using the IEP to Build Skills in Self-Advocacy and Disclosure”. Stephen Shore shares his own personal experience: “As far as disclosure is concerned I had it easy…… My parents used the word “autism” for as long as I remember.”

Stephen Shore explains this in more detail in a chapter of another book entitled *Voices from the Spectrum: Parents, Grandparents, Siblings, People with Autism, and Professionals Share Their Wisdom* (edited by Cindy N.Ariel and Robert A. Naseef, Jessica Kingsley Publishers). “My parents also saw to it that I knew exactly why I saw this professional and why things were different for me. They used the word “autism” around the house just like any other word. In doing so, disclosure never became an issue. I’ve known ever since age five or six that I had autism and that’s what led to my differences in school, home, and in the community. Proper disclosure to the person with autism of their condition is vital to building good self-awareness and esteem leading towards developing skills in appropriate self-advocacy…. Having good knowledge of one’s strengths and challenges at an early age plants the seeds for developing self-determination as well as building a foundation for learning how to successfully advocate for one’s needs in a way that is easy to understand by others. Realizing that my having autism is neither bad nor good but just something to take the positives from is yet another gift I have received from my parents.”

In chapter 3, Stephen advocates for parents and educators to teach students actively how to live best with their condition. His goal is to help persons on the spectrum and others working with them to use (Individual Education Plans) IEP’s as a way to develop disclosure and advocacy skills. These skills will help them throughout their lives. He provides a number of visual tools including graphs, plans and examples to assist the student to a greater understanding of their strengths/needs. He explains how to relay these to others in order to lead to mutual understanding and accommodations for learning. He feels that, by giving students some responsibility in the IEP, it makes their educational experience more meaningful and leads to a sense of self-determination, along with children teaching themselves self-advocacy and disclosure skills.

I found this book helpful as I have been asked by a number of parents if and when to tell their child about the diagnosis, or their strengths and challenges. How much information we provide to our children about their diagnosis or challenges and strengths will depend on a number of things including the understanding of the child. Every child is different. This book and other books provide good reference points for when and how to explain to your child about his/her diagnosis or strengths and challenges.

*This book is available at CPRI’s Family Resource Centre*