

No Limits

February 2006

How do we talk to our children about the attributes that make up their “disability”, and the labels those attributes bring with them? How should we discuss what makes their needs “special”, as opposed to the needs of their peers and siblings which are deemed “typical”? Answering these questions - and following up with these discussions - is vital to both our children’s and our own understanding of how we fit into the world, and affect how we envision our future in it. There are no simple or universal answers.

As I’ve learned from the experiences of many families who have and are dealing with these issues, I’ve seen a wide range of approaches. Some, in an effort to demystify differences and empower the child, have made it a part of ongoing discussions from a young age. Others have decided to not talk about it at all out of concern to avoid unnecessarily creating a sense of difference and isolation that may not otherwise exist. Some wait until they think the time is right to initiate a comprehensive sit down discussion of the condition. Others wait until their child broaches the subject, and then have a series of short discussions. What works in one situation may or may not work in another. Some families have made progress with more than one approach, and may have struggled with just as many others.

Of course, the children’s ability to communicate their own concerns and understand what the adults are attempting to communicate to them is crucial to the process. Also, their social experience with peers and siblings often colors their willingness to engage in discussing and understanding issues of difference and disability.

Tony Atwood, recognized worldwide as an authority on Asperger’s Syndrome, wrote on this subject, “When do you inform the child that they have Asperger’s Syndrome? There is no simple answer. Very young children will not have the maturity to understand the concepts. Older children may be extremely sensitive to any suggestion they are different. Their vehement denial of any inadequacy in social abilities is more an attempt to convince themselves than others. The answer may be to tell the child when they are emotionally able to cope with the information and want to know why they have difficulties in situation that other children find so easy. Sometimes this should be undertaken by parents, sometimes by a professional.”

While the specifics may differ when interacting with a child who has a condition other than Asperger’s Syndrome, Atwood’s idea of finding the right time, place, people and level of ability, interest and maturity strikes me as useful in figuring out how to proceed.

I’d like to initiate a way we can all learn from each other about all of this. What has been your experience in explaining these issues to your children, their siblings and their peers? What have they communicated – however they do communicate - to you about their experience of living with a “disability”? How have your discussions of these issues affected how you and they look to the future?

Please let me know what you'd like to share with other families, professionals, educators and other supporters. and I'll put together some of your responses both for a future newsletter as well as look for other ways to communicate with each other. Make sure to let me know if it's okay to share your comments publicly, and if so whether you want to remain anonymous. Here's how to contact me:

e-mail: inclusion@fsrcdane.org

regular mail: Family Support and Resource Center
Community Inclusion
101 Nob Hill Road, Suite 201
Madison, WI 53713

Telephone: 608/237-7639