

CFAN 2007 Workshop

Summary of Presentation: Parents using stories to advocate -Sue Robins, Parent Representative, Glenrose Rehabilitation Hospital

Sue Robins gave a half hour presentation to the CFAN group entitled *Parents using stories to advocate*. The purpose of the presentation was to share her story about her son, Aaron (who has Down syndrome), and talk about the many hats she wears and the types of the stories she tells about him.

Here are some main points:

- Her son, who happens to have a disability, isn't broken. It is the systems around him (like schools, hospitals) that are broken.
- Because of this, Sue uses stories to advocate for Aaron. She does it as a mother, as a freelance writer and as a Board member.
- She gave examples of the many arenas where she tells Aaron's story – to health professionals at clinic visits, when talking to new parents, when discussing Aaron's school goals, when trying to get funding from the provincial government.
- She tells his story to help others understand him, to get quality medical care and therapies, to educate, market and raise awareness about Down syndrome, and to bust myths that are out there about Down syndrome.
- As Aaron's mother, she wants to impart the high expectations she has for him, focus on his strengths, not deficits, share hopes for the future, emphasize the value of people with disabilities and help change policies and laws. She feels it is important to stress that *all* children should be celebrated.
- So how does one craft these stories? Use the simple who, what, when, where, why, how from your junior high English class days.
- The who is the audience – who are you talking to?
- The what is the content. Think about tone. Sue shared that she uses different tones, depending on her audience. When she talks to strangers, she's overly positive about Aaron. Talking to government funding agencies, she has to be very negative and focus on Aaron's disability (this is especially exhausting). Only when talking with other parents can she be really honest and realistic.
- The how: some hints about telling stories: be chronological, set the stage by introducing the characters, have an interesting 'hook' at the beginning to get your audience's attention, repeat your top two points, and keep it personal.
- She recommends using handouts or PowerPoint, because most of us are visual learners, and believes in the power of photographs. Keep in mind that most health care professionals, for example, see our kids only when

- they are sick. If you show them when they are well and engaged in activities, that helps their perception of what life is really like for you.
- Some pitfalls to telling these stories – fatigue, misconceptions in the media, you may open yourself up to criticism, and it can be emotional for you to talk about such a topic so near to your heart.
 - So how do you handle emotion or crying? Practice, practice, practice, remember to breathe, stop to compose yourself and explain to the audience you may need a few moments. There's no shame to tears.
 - The benefits to telling our children's stories – help increase understanding, develop relationships with those who work with our kids, help other parents feel less alone, stories can connect us as human beings and influence change.
 - Don't forget to ask other's permission to use their stories, respect confidentiality and see if your child can be his/her own self-advocate. Those stories are especially effective and powerful.
 - Sue's presentation ended with a quote:

For the sakes of our children, we must strive to be patient with those whose experiences have not given them access to our perspectives.

It is our duty to lead these people to a fuller understanding of the beauty and ability within our children. To do this we must become effective advocates.

-Jennifer Bollero, parent advocate, writer, lawyer, 2002

Any questions? Contact Sue at sue.robins@shaw.ca.