

## **Opening Remarks by Jan Lutke, Conference Chair**

(the general welcoming and housekeeping  
remarks have been edited out)

Adults with Fetal Alcohol Spectrum Disorders: Swimming Upstream -  
A Reality *Check*  
First National Conference on Adults  
Vancouver, B.C., Canada; March 25, 26 and 27, 2004

### ***PURPOSE OF THIS CONFERENCE***

If "a society is measured by how  
it treats the least of its members",  
then  
adults with FASD are not only among the least, they are also, by default,  
the last of the least

I am the parent of 8 diagnosed children who are over the age of 20. The following remarks that I am going to make are deeply personal in nature. However, I believe all of my remarks also speak for the many other families I know who are parenting adult children with FASD. This is the "*reality check*".

When my children, *who each, by good fortune, had the advantage of a diagnosis which allowed us to know what we were dealing with* were growing up, I thought things were hard to do, but doable. There may not have been much in the way of support or service, but they were, after all, children, and that meant at least some leeway in various systems to help them. I knew their difficulties and problems, but I also knew their gifts, their talents, their strengths, and what they had to give, if we were willing to value them. I learned how to make the systems I encountered work, to the best of their capabilities, for my children's needs. I could do that *because there were systems, and those systems had both capacity, and a willingness to be flexible and to bend the rules to accommodate children.* I naively and *mistakenly*, expected that, as adult Canadian citizens with a diagnosed *birth* defect condition, in a country with wealth and resources, and where, in the West in particular, FASD is supposed to be "understood", they would, as their "right" have these same, but different, needs for service and support addressed.

*Never did I imagine that when they became adults:*

Disability would somehow cease to exist because they hit the age of majority (I am sure every parent in this country who has a child who is deaf, blind or in a wheelchair will be pleased to know that as soon as their children become adults, they will experience the "age cure" and be able to see, hear or walk)

Never did I imagine that I would have to "prove" over and over again that they still had FASD, or ever had it to start with

Never did I imagine they would have no place in Canadian society beyond the farthest fringes or jail

Never did I expect that even for those children with FASD who had had optimum environments and who are "success stories" in FASD, there would be nothing for them; no "reason to get up in the morning"

Never could I have imagined that the prison system would refuse to accept information about a diagnosis because it did not come from my son himself

Programs would never see themselves as failing to meet my adult child's needs, only my child as the one with the problem; the "failure"

That doctors, dentists, lawyers, probation officers, counselors and other assorted professionals would, in their misplaced quest to make my children like everyone else, insist on allowing my children to fail, and fail repeatedly, before they would listen to what they needed to know - often far too late and with my children paying the price

The expenses involved with my children would go up, *way* up, not down

Accessing social assistance supports and disability social assistance supports would become a full-time nightmare:

- the process is demeaning at best

- adults with FASD are unable to access services without someone to do it for them, and systems refuse to allow this

- the disability is usually not obvious, therefore, systems "gate-keepers" deny even initial access

- the process is complicated and costly

- when asking for help to pay for \$670 of non-covered antibiotic prescription meds, offered a \$20 "crisis grant" (the short sightedness of this - i.e. no meds leads to hospitalization at thousands of dollars/day)

- workers change far too often and few, if any, have *any* training to work with those with *any* disability, let alone FASD

- observation in an Income Assistance office is an eye opener as to the lack of respect for marginalized and disabled people

I never expected that my children would be assumed to be abusing the system just by virtue of asking

Never would I have believed that children with FASD and *thus a disability*, who had grown up in foster care, could be cast aside by their legal parent and left adrift, without resources, money, supports, employment, someone to talk to or a place to call home; or that

Systems would penalize my children for behaviours directly related to FASD

It never occurred to me society would insist that sooner or later, my children would "have to learn", which assumes my children are lazy, uncaring, unmotivated, irresponsible and non-compliant individuals who just "need to get with the program, grow up, take responsibility for themselves and get a life"

I did not expect that those I know and may have to rely on would believe that I am "making excuses" for "bad behaviour" simply because my children are now adults

Never did I expect that other people who *had* made allowances for behaviour in my children would now refuse to do so on the basis of a change in age, and the older they get, the worse this becomes; or that

Extended family would become "as far away as possible" family

I could never have imagined, or believed, that society-at-large would find it so easy to manipulate, intimidate, victimize and yes, brutalize my children, and fail to see the wrong in that

I never expected that my "support" - which keeps them *alive* - would be considered "enabling" and something to be actively discouraged

It did not occur to me that systems in place for adults with other disabilities would be unable, and in *many* cases unwilling, to serve my children's needs

I would not have believed that systems criteria for eligibility would be so rigid; that the "creativity" in access for children would be non-existent for adults; and

It never entered my mind that systems would seem to be unable to adapt to FASD; or that new systems would fail to be developed as a matter of logic and common sense to address an emerging, costly and large demographic

I never expected the insistence on "evidence based practice" would be used as an excuse not to fund innovative and possibly life-altering/saving programs for adults - especially since there is no "evidence" because there is no "practice"

Never, in my darkest moments, would I have thought that systems would prefer to maintain the financial status quo of total marginalization rather than fund service delivery to improve quality of life and both the *desire and ability* of adults with FASD to contribute to society

I never could have anticipated that, after all these years, I would still have to fight, every day, to meet the needs of my children who are now adults;

That I would still need to be available 24/7 because no one else is

I would not have believed my children would be *dependent* on my ability to continue to earn an income to defray their costs of living because not one of them has an income of more than \$9,500/year - and I challenge any one of you to live on that amount of money in B.C. even with the very best of budgeting skills, something clearly not in evidence in my children

I could not have anticipated that systems will not allow for financial management of my children's money in the absence of a finding of incompetence - which they are not - and which *directly* leads to huge problems in every area; and

I would *never* have believed that I can never become ill, old or exhausted and I can never retire; heaven forbid I should die

I could not have known - and would never have believed -that I would have, by my age, exhausted all my savings, used up all my resources, be broke and more in debt than at any time in my life; and that

I would be the total, entire, complete, all-encompassing all-service delivery system for my children if I did not want them dead, on the streets or in jail

When the family *runs out* of resources - financial, mental, emotional, physical - *and it always will* - everything fails - there is no safety net

I AM TIRED OF THE "STATUS QUO".

*REALITY CHECK: It is not the children: It is the system that is the problem!*

*The children have not grown "up" - they have grown older!!*

No one has been addressing their specific and unique needs and issues. They are, by default, to quote retired judge Cunliffe Barnett, the "*orphan children of disability*"; disposable citizens.

We must focus our efforts and direct future planning *so that my children, and all the other adults with FASD can take their rightful place in Canadian society with the respect and supports due all - not just some - but all - disabled Canadians.*

Research on adults is very limited. Evidence based practice does not exist - but *practice based evidence* does - and that will be the focus of the next conference on adults planned for 2006.

This is the challenge to all of us - what is it going to take to get each and every one of us, and the multiple systems in society, not just mobilized, organized, able and willing to deal with this issue in a comprehensive, targeted and meaningful way, *but actually funding and doing what we need to do* in a manner that will allow my adult children - and all the other adults and those who are children today but who *will* grow older - to live, to partake, to contribute, to belong and to enjoy life - in other words, to have what each and every one of us in this room takes for granted. To do anything less is unethical and unconscionable in any society that truly believes in equality.