

## Parenting with Fetal Alcohol Spectrum Disorder

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Received: 30 May 2009 / Accepted: 23 November 2009 /  
Published online: 8 January 2010  
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**Abstract** This paper focuses on issues associated with parenting and living with FASD. It is based on a larger research and video production project that examined the challenges, accomplishments and support needs of adults with FASD in relation to parenting, employment and the legal system. Using theoretical sampling techniques, in-depth, face-to-face interviews were conducted with a total of 59 people from 5 diverse communities in British Columbia; of these, 15 were adults with (suspected) FASD. Findings presented in this article relate to parents' hopes, goals and accomplishments, parenting challenges, experiences with the child welfare system, and perceived barriers to support, including policy-related barriers. Findings also revealed prevailing ignorance about the nature of FASD and the day-to-day support needs of those living with FASD, which potentially have profound implications from both a health and a social justice perspective. For example, parents experienced reluctance to seek assistance for their secondary disabilities related to FASD (e.g., substance use or mental health problems), for fear of that their needs for support would be viewed as evidence of their parenting incapability. Highlighted will be directions for positive policy and practice-related change in working with parents with FASD.

**Keywords** Fetal alcohol spectrum disorder · Parenting challenges · Parenting supports · Adults living with FASD

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term that refers to the range of birth defects and neuro-developmental disabilities resulting from prenatal exposure to alcohol. Several diagnostic terms are encompassed by FASD, including Fetal Alcohol

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Syndrome (FAS), Fetal Alcohol Effects (FAE), Alcohol-Related Neurodevelopmental Disability (ARND), and Alcohol-Related Birth Defects (ARBD).

There is growing consensus that FASD needs to be understood as a permanent and invisible physical disability with behavioural symptoms (Malbin 2002). That means that people with FASD have significant brain differences that give rise to disability because of problems in a variety of areas, including cognition, memory, impulsivity and attention. Because the brain disability is permanent, FASD does not get outgrown, and the above primary effects are not “cured”.

At the same time, children and adults with FASD are extremely heterogeneous. There are tremendous individual differences in people’s strengths and in the nature and degree of people’s difficulties and thus the disabilities experienced. For this reason, understanding each person’s unique strengths, learning styles, learning difficulties and challenges, and life experiences, is essential.

Since its initial identification as a medical entity in 1973 (Jones et al. 1973), the preponderance of research relating to FASD has focused on the physiological and clinical indicators of FASD, and on the effects of FASD in children. However, in 1996, Anne Streissguth and her colleagues published groundbreaking research that conceptualized the difference between primary disabilities and secondary effects associated with FAS, based on longitudinal assessments of young adults with FASD. Primary effects of FASD include: poor short term memory; speech and language disorders; poor judgement and problem solving abilities; difficulties in relating behaviours to consequences; difficulties in generalizing information, forming linkages, and abstract reasoning; difficulties in planning and organization; impulsivity; and social and emotional challenges, including difficulties in reading social cues; lack of boundaries; trouble with understanding and expressing emotions (Burgess and Streissguth 1992; Stratton et al. 1996; Streissguth et al. 1996; Weiner and Morse 1994).

Secondary behaviours, by contrast, were defined as difficulties that a person is not born with, but that are linked to the primary effects of FASD. The secondary effects studied in Streissguth’s research included mental health problems, alcohol and drug problems, troubles with the law, school drop-out, employment difficulties, and “dependent living” (Streissguth et al. 1996). Streissguth’s distinction between primary and secondary effects suggested that secondary effects could be reduced and even prevented from occurring given improved community and professional understanding, as well as adequate and appropriate interventions. Parenting is an important opportunity to begin interventions that can minimize secondary behaviours and promote coping with neurobehavioural disabilities.

In Aboriginal communities, challenges in parenting with FASD are compounded by the effects of colonization. However, the unique strengths of Aboriginal communities are reasons to approach parenting with FASD from a wholistic and indigenous perspective. FASD finds its roots in the colonial history of Canada. Colonization, racism and the deterioration of First Nation political and social institutions, the suppression of traditional spirituality, culture and language, the apprehension of children and loss of traditional lands and economies is the legacy of Canada’s settler history (Van Bibber 1997). The residential school system proved extremely effective in destroying cultural pride and self-identity, in obliterating connections with traditional languages and in disrupting and severing family relationships (Rutman et al. 2000; Tait 2003). The current health and socio-economic conditions trace their beginnings to these historic events. What is less obvious when addressing issues such as FASD is the rich culture that existed before colonization, a culture so vibrant that its distinct nature lives on today. Much of the language and traditional practices have gone with the passing of each elder; however, ceremonies, traditional

knowledge and language are alive or are being revived in many communities. First Nation people understand that health and well-being are tightly linked to strengthening the unique traditional knowledge and practice of the ancestors. Among these practices are traditional parenting practices and knowledge. In view of these realities, discussions of FASD in Aboriginal communities cannot take place in a vacuum.

Recent Canadian and international literature emphasizes the difficulties in obtaining accurate population-based prevalence rates, and methodological flaws have been noted, in particular, in prevalence studies involving certain populations, including Aboriginal peoples (Roberts et al. 2007). Nevertheless, the currently accepted estimated prevalence rate of FASD in North America is 9.1 per 1000 live births (Calgary Fetal Alcohol Network 2005; Sampson et al. 1997). As such, Fetal Alcohol Spectrum Disorder is viewed as the leading known cause of congenital brain damage in the Western World (Abel and Sokol 1987).

These estimates suggest that in Canada, there are probably over 300,000 people currently living with FASD. Moreover, given that there are currently close to 26,000,000 people over age 15 living in Canada, it is estimated that approximately 260,000 adolescents and adults living in Canada have FASD (Abraham 2005; Lutke and Antrobus 2004). Chances are, a high percentage of these adults have or will have children. Thus, the number of parents who themselves have FASD is significant.

Despite this, relatively little attention has been paid to issues in adolescence or adulthood for people with FASD. Indeed, in view of the above statistics, the paucity of literature focusing on the experiences and support needs of parents with FASD is noteworthy and lamentable. At the time that our project team commenced our research, there was *no* literature known to the authors that focused specifically on the parenting experiences and issues for people who themselves had FASD. This knowledge gap is all the more distressing given that parenting issues have been repeatedly identified as being of great concern to adults with FASD, their support people, and service providers who work with them (Abraham 2005; Ford et al. 2001; Rutman et al. 2002, 2005).

To address this knowledge gap, our project team undertook a research and video production project that aimed to examine the challenges, accomplishments and support needs of adults with FASD in relation to parenting, and to identify programs, practices and policies to better address these parents' needs.<sup>1</sup> This article will share findings relating to the accomplishments, experiences and challenges of parents living with FASD, as well as some of the approaches and supports identified by parents with FASD as being helpful to them and their families.<sup>2</sup> Finally, this paper will explore issues relating to FASD and parenting within an Aboriginal context and perspective, including barriers faced by those living with FASD and by communities in relation to FASD prevention, as well as positive strategies and directions for change.

## Methodology

In keeping with research exploring people's lived experiences, the project employed a qualitative research design. The project also was informed by video ethnography as a methodology; video ethnography involves utilizing video as a means to construct audio visual representations of social life (Goldman-Segall 1998).

<sup>1</sup> This study was one of three inter-related projects undertaken from by the project team; the other two focused on employment-related issues for adults living with FASD, and on FASD and the criminal legal system.

<sup>2</sup> Expanded discussion of challenges associated with parenting with FASD, as well as useful parenting-related supports and strategies is contained in Parenting with FASD (Rutman et al. 2005).

In-depth, face-to-face interviews were conducted with a total of 59 people from 5 diverse communities in British Columbia in order to gather information for our three inter-related projects focusing on the experiences and support needs of adults living with FASD. In keeping with a number of qualitative methodologies, we employed theoretical (i.e., purposeful) sampling techniques whereby emphasis is placed on selecting appropriate, “information-rich cases” for in-depth study (Morse 1994; Sandelowski 1986).

Of the 59 people interviewed:

- 15 were adults with (suspected) FASD. Of these adults, 10 were Aboriginal and 5 were Caucasian
- 8 were support people of the adults (e.g. parents, partners)
- 36 were multi-disciplinary service providers/key informants (perinatal program staff, FASD-related program staff, social workers, community support workers, adult education educators/administrators, employers, lawyers, judges)

In keeping with other studies focusing on issues for adults living with FASD, we did not require a diagnosis/assessment of FASD as a criterion for participation. This is because the majority of people living with FASD have not had a formal diagnosis. To ignore those who lack a diagnosis would be to further marginalize and dismiss the experiences of those living with FASD. Nevertheless, the prospective participants needed to self-identify as having FASD, and, if a support person was involved in the research, the support person needed to confirm that the participant’s behaviours were consistent with FASD.

Semi-structured interviews were carried out as guided conversations about people’s lives and experiences (Patton 1990). Interviews ranged in duration from 30 to 90 minutes and were carried out in a location of the participant’s choice. In some cases, we conducted more than one interview with a participant, to capture changes that had occurred over time in the person’s life. Finally, at the request of participants, we carried out several small group interviews and two focus groups with service providers. Interviews were videotaped and audiotaped, with participants’ consent.

## Findings

### Parenting Hopes and Goals

To provide a context for discussing participants’ experiences as parents, we begin by sharing themes relating to participants’ hopes and goals for themselves as parents. Central to participants’ goals was their desire for their children to become good people who would have a life that was better than their own. One parent spoke very eloquently about his parenting goals:

I don’t want them to skirt on the edges of society like I did. I want them to be citizens instead of being spectators.

A strong, related theme was participants’ desire to “break the cycle”. The ‘cycle’ was conceptualized in various ways. For some, it referred to the cycle of addiction and drinking around children; for others, it was about being abusive or neglectful toward children; for others, it meant involvement with the foster care system; and for others, it meant not being part of a child’s life.

It’s just kind of: Don’t be the dad that my dad was to me.

Moreover, it was evident in participants' comments that their keen wish to break the cycle, however defined, was motivational and for some was a strategy that they used to help stay on track and employ positive strategies to deal with challenging situations. As one mother stated:

When I grew up, my mom and dad used to always drink around me, and I don't want that. I want to break that cycle, and I don't want to live like that. ...I don't want my kids to have to go through that. So I don't really hang around people who drink or do drugs.

Another parent realized that she needed time for self-reflection so that she could identify ways in which she could raise her children differently than she had been raised:

Before, I was raising them because I had to, and because my mom raised me this way, or whatever. I'm going to raise my kids because I love them...and I want to raise good people. And in order for that to happen I have to be a good person myself.

### Parenting Accomplishments and Strategies

As an initial question in the qualitative interviews, participants were asked about their parenting accomplishments, i.e., what made them feel proud of or good about their parenting. Many participants emphasized that just having their children remain in their care, or getting their children back into their care or custody was, for them, a significant accomplishment. This was particularly true if the child had been removed from the parent's care or if the parent's worker had questioned his or her ability to look after the child. Along similar lines, having their children show affection and attachment, and being part of their children's lives, was important for some participants, and all the more so for participants who had not had this experience in their own childhood.

Interestingly, many of the themes that emerged as accomplishments could be linked to the daily living strategies that participants identified as being helpful to them. In other words, participants felt a sense of accomplishment when they were able to engage in what they understood to be positive parenting and/or a healthy lifestyle. For example, a number of participants were extremely proud of having learned strategies to calm themselves down and control their temper. Taking a "time out" to collect themselves or their emotions was both a parenting strategy and, when practiced consistently, an accomplishment.

For parents who struggled with drug or alcohol problems, finding ways to cut back or avoid using substances was identified as a highly significant parenting accomplishment. These parents realized that that they came to the attention of child protection authorities in large part because of their substance use problems. Thus, when they were able to put into place strategies that helped them stay clean, such as steering clear of people who used drugs or alcohol, they were also working toward achieving their parenting goals of "breaking the cycle":

I mostly hang around my sister-in-law and my brother and people around here who are sober. ...It's been almost 2 years, going on three, being away from drinking and doing drugs. I feel more happy and healthy.

Other parenting accomplishments and parenting strategies that participants identified as helping them included:

- Using memory aids such as calendars, schedules, organizers, post-it notes
- Using self-talk and other strategies to make transitions within the day's activities
- Having consistency in the day's schedule and activities

- Applying guidance techniques consistently, such as setting boundaries and focusing on their children's positive behaviours.

Incorporating several of these strategies together, one parent stated:

I write down everything, detail by detail, that needs to be done. So, we all have things that we need to do. I never thought that making sure that their daily schedule was written down was going to be as important to them as it was to me. I mean, they don't have any disabilities; I do.

### Parenting Challenges & Barriers

The participants in our research spoke openly about various parenting difficulties they faced, some of which they themselves attributed to FASD. In examining the types of challenges experienced by parents with FASD, Streissguth et al.'s (1996, 1997) framework on primary and secondary effects of FASD is a useful conceptual tool. At the same time, participants described a number of challenges that they faced that arose from the impoverished social conditions in which they lived, or as a result of negative societal attitudes, as well as unsupportive child welfare policies, which hindered their efforts to access the support they needed as parents. Thus, in addition to the primary and secondary effects of fetal alcohol, following is a brief discussion of the gamut of challenges and barriers experienced by parents living with FASD.

Primary effects of FASD that impacted parenting included problems with: memory and organization; perseveration; planning; generalizing from one situation to another; using consequences effectively; understanding the concept of time; registering and integrating sensory cues such as hunger, temperature, and pain; and temper/patience and impulsivity. As discussed in further detail elsewhere (please see Rutman et al. 2005), the ramifications of these primary effects of FASD can be huge, and have the potential to jeopardize the family's health and safety if appropriate safeguards and supports are not put into place.

Yet, in addition to dealing with primary effects of FASD, most participants also experienced a number of parenting challenges that could be conceptualized as secondary effects of FASD. These types of parenting challenges were most often inter-connected and included several secondary disabilities identified by Streissguth et al. (1996), as well as secondary effects discussed by other FASD researchers and educators (Boland et al. 2002; Lutke and Antrobus 2004; Malbin 2002), such as: alcohol and drug use/addiction; lack of positive role models and social supports; abusive domestic relationships; transience and homelessness; and poverty and lack of resources.

Several participants in our project struggled with addictions issues that had negative ramifications for their parenting, such as "not being there for [their] children" and/or child neglect. For these participants, substance use was also a very strong risk factor for other secondary effects associated with FASD, including homelessness and involvement with the criminal legal system. As such, participants themselves recognized that their substance use was a significant precipitating factor in losing custody of their children.

Another strong theme in the interviews was that many of the participants never had experienced or observed a positive role model in relation to parenting. Consequently, what was 'normal' to them was the unhealthy and potentially harmful parenting approaches to which they had been exposed as children. Other participants spoke of being raised by parents who themselves were likely affected by prenatal exposure to alcohol, and/or in families dealing with multiple generations of addiction. For Aboriginal participants, the devastating and multi-faceted legacies of the residential school experience robbed

generations of Aboriginal families of knowledge of culture, language and traditions, including those related to raising children (Rutman et al. 2000). In one mother's words:

A lot of things I did wrong which I thought was right: yelling at them, being aggressive, I learned from my parents, thinking that what they were doing is right.

A significant number of participants in this project, as well as in our previous research with adults with FASD (Rutman et al. 2002), had experienced one or more types of abuse in childhood, adolescence and/or adulthood. Young women in particular were vulnerable to victimization in social and sexual relationships, and their craving to belong in a group and be accepted, loved and taken care of heightened this vulnerability and their risk of engaging in unhealthy or unstable relationships (Copeland and Rutman 1996). Other factors that increase the social vulnerability of adults with FASD are their compromised judgement (particularly in relation to assessing whether others may take advantage of them), their lack of role models or experiences of healthy relationships, and difficulties with communication and conflict resolution (Hume et al. 2006). In terms of their parenting, participants struggled to navigate their own personal relationships and safety issues, while attending to their children's safety, attachment issues, and emotional development.

Other secondary effects of FASD that affected parenting were transience and housing instability. Moreover, for a number of participants, grinding poverty, possibly linked to or stemming from addiction problems, contributed to their being evicted and, in the words of participants, to "everything getting disconnected" and their "bouncing around quite a bit". For some participants, these factors became red flags that kept them in the radar of child welfare authorities.

### Challenges Associated with Societal Attitudes or Expectations

In addition to dealing with parenting challenges related to the primary and secondary effects of FASD, participants confronted challenges associated with how FASD was viewed—and misunderstood—by society.

Being stigmatized because they had FASD was an experience voiced by most participants. Participants were particularly distressed when workers and others seemed to make little effort to get beyond the label of 'FASD client', to get to know them as individuals, and in particular to identify and focus on their strengths and challenges as parents. In these parents' words:

(Ministry workers) did show up on my doorstep, and they did have some problems for about 6 months. They were totally doubting who I was, and maybe I shouldn't have the kids. Because I had FAS, that made me a bad person.

Workers make me really frustrated; they don't know who I am really. All they've got is my name on a piece of paper and like just a little bit of information. They don't know me personally. They don't know things that I've accomplished and overcome; you know, what my life's been like.

Participants also felt as though their parenting was highly scrutinized for evidence of mistakes or misdeeds, both by the state (represented by Ministry or contracted workers), community service providers and the public at large. For example, one mother told of an incident in which a misplaced bottle was viewed as an indicator of neglect:

There was a bottle that I found in the stroller that was there for maybe two weeks or something. I asked them, 'Can you wash this out? It was sitting in the stroller for two

weeks. I was looking for it and I didn't know where it was.' They wrote down I was giving [my kids] sour milk and all that, and the kids were neglected and everything.

At the same time that participants were feeling pre-judged, they observed that, because FASD is an invisible disability, other people all too often *over-estimated* their abilities or trivialized the degree or nature of their disability. Along these lines, participants believed that some social workers or service providers perceived them as being unmotivated or as willfully flouting directives, rather than recognizing that the instructions had not been understood in the first place. Participants further believed that parents sometimes paid a steep price for workers' and service providers' ignorance about FASD, particularly if child welfare authorities perceived adults with FASD as being non-compliant, rather than in need of ongoing assistance and support. As one support person stated:

I think that there is a tendency for people to overestimate the abilities of people with FAS. They think and perceive that someone will be able to understand what they're being told and be able to follow instructions, and sometimes it just isn't so. ...It's not a matter of not wanting to; they're just not able to.

#### Policy-Related Barriers for Parents with FASD

Finally, based on participants' stories of their struggles, it was apparent that unsupportive child welfare policies created systemic barriers that contributed to difficulties in parenting with FASD. In particular, policies that prevented people from accessing parenting-related supports and resources (e.g. respite services or specific parenting programs) unless they were viewed as being at high risk of having their child apprehended or already had been investigated by the child welfare authorities, were viewed as being at odds with the ongoing support needs of parents with FASD. As one mother stated in response to why she did not seek respite services from the Ministry:

I don't want them to think that I can't take care of my kids and that I'm abandoning them again. If I'm in a really tight situation, then I would turn and see if I could get respite, but that would be my last thing.

Similarly, a support person commented:

What happens is, parents get so scared of losing their children they're afraid to ask for help. ...They don't want to lose their children; they just want help raising them.

A second major policy barrier for parents with FASD concerned eligibility criteria for Community Living resources that were, in practice if not in actual policy, IQ-based (i.e., adults were only able to access these resources if their IQ was lower than 70). Community Living resources that were identified by participants as being highly useful to parents with FASD included supportive housing, respite that was not time-limited, and parenting programs that were designed for people with cognitive disabilities. However, as has been shown in the literature, for people with FASD, IQ is a poor predictor of day to day functioning (Russell 2003, 2007). Thus, barring access to these services for parents with FASD was a significant barrier to success in parenting and interdependent living. As one support person said of her son:

He's never been tested, so we don't know if he has under-70 IQ. If you're not in that low percentile, you don't get any services. So he's on his own.

A third policy barrier noted by participants was that parenting resources and supports, including financial resources, were differentially available to different "categories" of



parents (i.e., foster, birth adoptive, and extended family, especially grandparents caring for grandchildren). For example, foster parents were able to access respite and home support workers, as well as financial benefits more easily than could other types of parents. By contrast, grandparents caring for their grandchildren typically had limited access to financial supports in parenting, even if they were caring for the child on a full time basis. As noted by participants in the research, these policy issues affected and compounded challenges faced by many Aboriginal families.

## Discussion and Directions for Change

Our existing policy context, coupled with prevailing ignorance about the nature of FASD and the day-to-day support needs of those living with FASD, has potentially profound implications from both a health and a social justice perspective. Foremost among these, illustrated in both this project and other research, was that parents experienced reluctance to seek assistance for their secondary disabilities related to FASD (e.g., substance use or mental health problems), for fear of that their needs for support would be viewed as evidence of their incapability, leading to their child being apprehended. Similarly, parents were afraid to seek a FASD assessment for themselves for fear of being labeled a “bad” or incompetent parent. This situation of mothers or pregnant women with addictions issues or health/mental health needs going “underground” for fear of scrutiny by child welfare authorities has been well-documented in the literature (Poole and Isaac 2001; Rutman et al. 2000), and points to the clear need for more supportive policies for these parents.

In addition, the findings of this research attest to the tremendous need for *ongoing* support for adults living with FASD, whereby access to the support is not gated by IQ-related criteria, but rather by functional need. These findings are entirely congruent with the emerging body of literature concerning the experiences and support needs of adolescents and adults living with FASD (Dubovsky 2008; FASSY 2002; Lutke and Antrobus 2004).

Other sources of support can be found in past family and community history. In traditional Aboriginal parenting practices, there was a broader responsibility than just the immediate parents. Aboriginal elders often speak of families and communities coming together to meet the needs of their children. Each member of the family had a role to play in raising the children. Within the community, the roles and responsibilities of family members extended to all the children in the community. Elders and family members will tell you that it “takes a community to raise a child” (Van Bibber 1997). The Royal Commission on Aboriginal Peoples and the Assembly of First Nation described a nurturing environment for early child development as follows:

In this early stage of development, children learned how to interpret and respond to the world. They learned how to walk on the land, taking in the multiple cues needed to survive as hunters and gatherers; they were conditioned to see the primacy of relationships over material possessions; they discovered that they had special gifts that would define their place in and contribution to the family and community. From an early age, playing at the edge of adult work and social activities, they learned that dreams, visions and legends were as important to learning as practical instruction in how to build a boat or tan a hide. (Report of the Royal Commission on Aboriginal Peoples, Volume 2, 1996, p 446–447.)

Many of these traditional child rearing practices still exist in Aboriginal families today despite the impact of five generations of residential schooling followed by decades of child welfare apprehensions. Elders, parents and community members talk

about the need for child care services to reflect the customs, traditions, values and beliefs of Aboriginal peoples, children must know who they are, they must be grounded in their culture, language and traditions.” (Greenwood and Shawana 1999, p. 2).

At the core of all directions for change is the need for a shift in our thinking about Fetal Alcohol Spectrum Disorder and our expectations for those living with it. Grounded in a conceptual framework of FASD as a brain-based physical disability, “thinking differently, rather than harder” has been the mantra of numerous publications and educational materials directed at those working with and caring for people with FASD (FASSY 2002; Malbin 2002). Our findings in this research echo the wisdom and the urgency of the message.

Participants’ recounting of their parenting goals, accomplishments, strategies and struggles pointed the way to a range of supportive programs and “wise” practices that need to happen as part of the shift in thinking. Supportive programs named by participants included: flexible, client-centred, outreach-oriented FASD prevention programs that worked with parents for years after the baby was born; teaching homemaker programs; life skills programs with staff who were knowledgeable about FASD; and child welfare workers who worked collaboratively with parents (Rutman et al. 2005). Wise practices included using a relational approach, being non-judgmental, non-condescending, and yet “loving honest” in order to bolster self-esteem.

From a policy perspective, recognizing the long-term cost-effectiveness of community-based supportive services that are accessible and not contingent on restrictive eligibility criteria is paramount. Similarly, shifting child welfare policies to enable families to access supportive resources further “upstream”, in keeping with a prevention and early intervention/support orientation is essential for parents with FASD and/or other disabling conditions.

At a program level, parenting education and support programs for adults living with FASD need to be grounded in a deep understanding of FASD as a neuro-behavioural disability. Programs that offer outreach-oriented support and advocacy and that use learning approaches that are hands-on and experiential generally fit with the needs of parents with FASD. Moreover, a holistic and culturally appropriate approach to working with parents with FASD is essential.

Lastly, the importance of recognizing the degree of diversity that exists among people with FASD, and the communities from which they come, cannot be overstated. It is imperative that we get to know people as individuals with unique strengths, needs and contributions. Not only is this vital in terms of policy development and service delivery, this message is key to relationship-building, community awareness and development, and, ultimately, FASD prevention.

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