



## **VOICES FROM THE FIELD - An Aboriginal View on FAS/FAE**

**Della Maguire, Executive Director and Founder  
Mi'kmaq First Nation Healing Society**

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### ***Aboriginal perspective***

“In the Aboriginal community, FAS/FAE is a partner, a family and even a community issue, because we are a collective society,” says Della Maguire, Executive Director and founder of the Mi'kmaq First Nation Healing Society in Hantsport, Nova Scotia.

The Mi'kmaq First Nation Healing Society is a non-profit organization serving Aboriginal communities. Della Maguire educates and provides training and support on a number of issues, including Fetal Alcohol Syndrome (FAS).

### **What are the implications of the research findings in the CEECD papers for your work?**

Maguire's main concerns about the CEECD papers are that:

- the research is mostly American; and
- there is a lack of Aboriginal content within this research.<sup>1-9</sup>

When we read the CEECD papers, FAS/FAE comes across as a women's problem. “There is a need for more sensitivity and it should be stressed that FAS/FAE is not only a women's issue,” Maguire states.<sup>1-9</sup> The Aboriginal people look at a community holistically and therefore they talk about the partner, family and community as well. All problems are considered collectively. According to Maguire, Aboriginal communities lack this type of research information. There is a strong need to go beyond what already exists. Aboriginal people should be more involved in the research in order to make it relevant to their communities. “The CEECD papers are a good starting point.<sup>1-9</sup> For the time being, I need to rely on the Centre's experts and add a cultural component and a cultural sensitivity when I present them in my workshops,” adds Maguire.

Della Maguire believes that a lot of Aboriginal communities are farther ahead than non-native communities in education on FAS/FAE and moving beyond the denial stage. “We are accepting the fact that FAS is in our communities even if we are all on different levels in terms of accepting the problem,” says Maguire. Travelling across Canada has allowed her to notice these differences in each province. For instance, at one of her workshops in Ontario, she asked how many participants had attended this kind of workshop before. Out

of 50 participants, only half had been to such an event in the past. Her approach in each workshop is regularly changed and adapted to meet the needs of the participants because even though the research has been out there for a long time, people are not hearing the right message. They know the basic facts (alcohol consumption during pregnancy causes birth defects), but do not realize the extent of the impact. It is Maguire's role to further educate Aboriginal communities and provide them with advice, strategies and additional information.

She knows some of the communities have problems with alcohol, but because Aboriginal people live in a collective society, it is a challenge to get them to speak up. They fear the entire community will find out about their problem. Because of this sensitivity, Maguire has designed her workshops "according to the basic principles of respect, understanding, caring, forgiveness and hope." Different communities throughout the country keep inviting her back and each time she visits, the workshops attract bigger crowds than when she first started 10 years ago. "Now, people want to know. They want this information. They are very curious about everything and ask very good questions."

**Where are the main gaps between research, practice and policy and how might they be overcome?**

Maguire identifies trust as one of the main gaps in practice. It is especially noticeable when non-Aboriginal people are doing the research or coming into communities to conduct prevention or screening programs. "There is a lot of fear around the trust issue. In the past, Aboriginal communities have been scrutinized and surveyed. It will take time to rebuild that trust," adds Maguire. Timing is also important and the communities need to feel safe. Researchers, service-providers and policy-makers need to be culturally aware. FAS/FAE is still a sensitive issue and should be "community-based at a community pace."

When a non-native society looks at health, they look at the disease or the illness and its treatment, while the Aboriginal concept of health focuses on physical, emotional, mental and spiritual wellness. "It is a whole different mind-set. In a sense, this difference reflects strongly on people who try to have their children diagnosed. They do not want to be labelled, but instead want to know what could help," says Maguire.

Through her travels, Maguire has noticed that organizations are still not educated enough and do not recognize the links between what they do and FAS. Practitioners and service-providers need to be better informed and educated. Maguire has the challenge to make sure they understand these links. "FAS/FAE is a lifetime disorder, and practitioners and service-providers need to look further ahead in the future."

Another issue that should be addressed is the use of screening tools and the way they relate to Aboriginal people. It is important to take into account the different cultural aspects, and screening tools need to be adapted accordingly in order to prevent misdiagnosis. "Researchers are not adapting the measuring scales. The tools used most of the time will not work because we have different cultural norms," says Maguire. Some physical features, such as eye slants and sometimes head size, can be part of the culture in

some communities. Standardized psychological testing for Central Nervous System (CNS) dysfunctions may also be inappropriate for Aboriginal people, especially for those who speak their own language. Maguire states that we should have “culturally appropriate” screening tools. She also has concerns about the community-based screening mentioned in the CEECD papers.<sup>1-9</sup> “How could this work in our communities if even our own native doctors cannot do it because of the lack of trust, confidentiality or just the difficulty of obtaining parents’ permission?” According to Maguire, Aboriginal people are not there yet.

Many Aboriginal communities have their own health clinics or health centres that provide parenting and family programs. For instance, in Nova Scotia, the Mi'kmaq Family and Children Services, a self-governing program, is responsible for the 13 Aboriginal communities in the province. This would be the equivalent of Family and Children’s Services in non-native communities. However, sometimes the services needed are only offered outside the communities, and this implies travelling, accommodation problems, language barriers, lack of support and racism. As a result of these numerous barriers, the individuals concerned do not receive the proper services.

FAS/FAE needs to be addressed on a national level because each province has its own criteria governing what can be considered a disability. “We need to look at FAS/FAE as a disability and have an agreement across the borders so the government can start developing some services around it,” Maguire says. “FAS is a lifetime disability,” she concludes.

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