

## **VOICES FROM THE FIELD - Reflections on Practice in the Field of FASD**

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### ***Service perspective***

The introduction to the CEECD synthesis on the topic of Fetal Alcohol Spectrum Disorders (FASD) describes it as an “avoidable” or “preventable” birth defect.<sup>1-9</sup> These descriptors imply that if a woman does not drink alcohol during her pregnancy, she will not have a child with this disability. It does not necessarily follow that it is possible to prevent alcohol intake during pregnancy. If we acknowledge that 82% of women of childbearing years drink alcohol<sup>10</sup> and most women generally do not plan their pregnancies, then it is unlikely that FASD can be totally prevented. Many women can stop drinking once their pregnancy is confirmed; however, some cannot. Given that women drink to cope with the experience of poverty, childhood abuse, violence, isolation and other painful life situations, and that messages about alcohol use during pregnancy are inconsistent, we need to understand that we are “swimming upstream” with our awareness and prevention campaigns.

It is certainly our experience that services for the birth-to-five population are limited. However, there are more services given to this younger age group than to children over the age of six or to adults. Services for individuals past the age of six are almost non-existent. It is my impression that in Canada, we put a great deal of emphasis on early intervention services that are delivered until age six and then terminated. It seems we believe that if intervention occurs early enough, potential deficits in functioning will be avoided and existing problems can be eliminated. Yet the research in this field indicates that FASD is a lifelong disability and therefore, support and intervention services need to be available over the lifespan.

Riley’s comments on community screening for FAS raise the issue of voluntary versus mandated involvement in screening programs and follow-up services.<sup>8</sup> Women often voice their fears about having child welfare agencies remove their children if they are identified as using alcohol during pregnancy. For this reason, many parents may be reluctant to give permission for the screening of their children. Further to this, Riley indicates that screening that doesn’t lead to diagnosis is of limited usefulness.<sup>8</sup> I would add to this that screening or diagnosis without intervention services to which families can be referred has ethical implications. Families believe that a diagnosis will open the door

to services for their children. Without ongoing intervention services, families are left with limited education and little support for understanding the complex nature of the disability.

We have learned that intervention programs need to be structured to meet the needs identified by families. They require flexible, confidential, tangible support services with voluntary participation. Intervention extends beyond the family unit to reach the larger service system surrounding them. It really needs to be multi-systemic to prevent secondary disabilities. Most families, extended families, schools, daycares and other community agencies know very little about FASD and how to intervene. Yet the avoidance of secondary disabilities depends on the education of those who comprise the child's world and the quality of their intervention. We have learned that education and advocacy work with all the systems surrounding the individual, such as school, daycare, income assistance and other organizations involved with the child and family, requires twice the amount of time spent in direct contact with the family. The level of involvement with all the various systems requires lower caseloads than most agencies are prepared to embrace.

I agree with Cole's comments on the need to evaluate the effectiveness of existing programs and services.<sup>5</sup> When developing our intervention program, we extrapolated from Sterling Clarren's\* concept of the "external brain." Many of our intervention strategies recognize the organic brain differences associated with the disability and, in the words of Diane Malbin\*, "try differently rather than harder." We focus on changing the environment surrounding the individual to accommodate to them. Our intervention looks at adapting environments by building in memory, creating predictable routines, adjusting expectations and teaching about the strengths and challenges of each child. Simultaneously, we assess the sensory integration of the child and provide remedial intervention. (Remediation is usually focused on changing the environment surrounding the child.)

We have learned that the education and advocacy components of intervention services in the field of FASD are not usually identified, yet they are an absolutely essential component and of primary importance when trying to avoid secondary disabilities. We know that secondary disabilities occur because the central people in each child's life lack an understanding of the neurobehavioural impact of prenatal exposure to alcohol. In our experience, people learn about the disability over time and need to be given bite-sized chunks of information as they can digest it. This has implications for the length of time an intervention program is available to a child, their family and the multiple systems surrounding them.

Parents need a partner to walk them through the process of educating the child's world about the disability. Parents soon burn out when repeatedly faced with educating the same school system, the same daycare, facing intolerant systems that punitively address their child's behaviour. Every time there is another transition in the family and child's life, there is an enormous educational component attached to the transition.

There is general consensus that much research still remains to be done in the field of FASD.<sup>1-9</sup> In my opinion, however, the research is substantial and years ahead of policy to

address this issue at the local or regional level or the availability of service programs. In spite of the “lifelong” impact of FASD, many affected individuals cannot access existing disability services. They are ineligible for educational supports in the school unless their behaviour is extreme. The family is not eligible for respite services unless their child’s Developmental Quotient is below a certain level. In addition, most service programs designed to address FASD specifically are still “experimental” in design and predominantly funded as pilot projects, without long-term funding commitments. There appears to be very little political will to fund programs to meet the needs of this population.

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