

BULLETIN

Raising awareness for fetal alcohol syndrome

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by DAN KEETON

You might say that Karin Cleven takes her work home with her. After a busy day as a supervisor at SHARE Family & Community Services Society, Cleven plows her energies into securing permanent funding for individuals with fetal alcohol syndrome and their families. Cleven's experience in counselling sparked her activism and her passion for helping those affected by FAS.

Karin Cleven Supervisor - Child & Family Programs SHARE Family & Community Services Society

"When I was in graduate school I studied FAS," says Cleven, who holds a masters degree in counselling. "But when I graduated and began work I realized there was nothing taught about how to support families with FAS children."

Fetal alcohol syndrome was identified in 1973, but there is still a vast ignorance on the part of the public, politicians, and even health care professionals about its effects and treatment. People with FAS are frequently misdiagnosed by doctors, Cleven says.

The syndrome is acquired in the uterus and can not be cured. It is often associated with mental retardation, but many FAS people actually have high IQs and, ironically, often fall between the cracks of social assistance because all financial support ends when they turn 19. Sufferers of FAS usually have problems recognizing the consequences of their actions, and because this condition is permanent, they require lifelong support.

"I met with parents and their stories just gave me the energy to keep on with this," says Cleven. "They'd visit counsellors and psychologists and often get blamed for being bad parents."

She recalls meeting with one adoptive parent of an FAS child. "She wasn't told [at the time of adoption] about the FAS. She found she couldn't get proper service or support anywhere. I felt like taking out a full page ad in the *Sun* about this woman and the trials she's undergone."

SHARE is located in the Tri-Cities area, serving Coquitlam, Port Coquitlam, and Port Moody. In October 1998, the community held a conference on FAS with more than 200 attending. Six committees were created, and all are still operating.

The committees, composed of parents and health care givers, deal with issues such as the training of professionals, community support, diagnosis and intervention, and a round-table group comprising 60-100 participants.

"I think we were ready for it," says Cleven of the strong community-driven effort. "We got parents involved and they're just amazing."

Cleven also sits on a provincial consultation group that meets three times a year to compare notes, offer mutual support and plan for the future. "People say they are really happy with the community's interest, but also they note a real need for provincial funding."

Individuals from the group are lobbying the province for continued, guaranteed funding for FAS people and families. They want a program of province-wide prevention, accessible diagnosis and assessment, and long-term support. "This is not the only deserving group," Cleven acknowledges. "And I think you shouldn't have to be a good advocate to get services. But unless you have these large lobby campaigns, it's hard to get funding for anything."

Cleven, a former outreach counsellor, has a full work day as supervisor of special services to children, one of several services offered by SHARE. The non-profit society was founded in the early seventies as a clothing exchange, and has grown to include a food bank, and several other programs and services, including speech and language therapy, ending violence against women, and several counselling programs.

"I'm doing this [FAS work] off the corner of my desk," says Cleven. But years of working with those affected by FAS has her determined to win steady financial support.

The Tri-cities community response group, along with members of the provincial consulting group, is mounting a postcard campaign. The postcard can be copied from the group's web site at www.fetalalcohol.net.

Cleven thinks fellow HSA members can make a difference by becoming involved. "We ask that they wait until September 9 [national FAS day] to mail them, and to continue mailing postcards until the next provincial election."

For more details, members can contact Judy Higham at higham@home.com or Karin Cleven via the HSA office.

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