How to Grow Your FASD Program & Diagnostic Clinic, from the Ground Up and on a Shoestring

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The learning objectives for this session consist in:
1. Sharing our experience to illustrate the development of an FASD program from the ground up
2. How to expand with little additional funding
3. How to develop programs and services by layers
4. Building in community engagement to enhance partnerships and awareness.

FASD Conference Syllabus

The incidence of FASD in Canada is estimated to occur in 9 out of every 1000 births resulting in more than 3,000 babies born with FASD. With a population of 235,000 Northwestern Ontario could have as many as 2,000 individuals with FASD, most of which are not diagnosed. The emergence of FASD as a recognizable health issue dates less than 30 years.

In 2001, the NorWest Community Health Centres (CHCs) responded to the request by community members to assist with the development of an FAS Coalition with approximately 20 partner agencies. We secured several grants and been involved in several initiatives that enabled NorWest CHCs to function as incubator for awareness, training, support and consultation.

As part of the Health Canada FASD Trainer’s role, our FASD Coordinator can provide non-medical assessment and referral for diagnostics. Since 2004, referrals have been made to the Fetal Alcohol Spectrum Disorder Diagnostic Clinic at St. Michael’s Hospital.

In 2007, we began holding FASD diagnostic clinic with St. Michael’s Hospital via telemedicine. Our diagnostic team has been trained by St. Michael’s Hospital’s FASD Clinic, initially with Nurse Practitioners to complete the facial feature measurement. We are now able to run our own diagnostic clinics. We diagnose across the lifespan. We follow the Canadian Medical Association’s Fetal Alcohol Spectrum Disorder Canadian guidelines for diagnostics.

From March 2009 to January 2014, the NorWest FASD Diagnostic Clinic has seen approximately 156 clients, with a confirmed FASD diagnosis for 131 clients. More than five new referrals are received every week. The diagnostic process is difficult to expedite and can take up to one year due to information gathering and validation, assessments and diagnostics.

The FASD Diagnostic Clinic at the NorWest CHCs is one of approximately 11 diagnostic clinics in Ontario, the only one in LHIN 14, and one of two clinics that diagnose through the lifespan in the

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province of Ontario. NorWest CHCs is likely the only Community Health Centre with FASD core competencies in the province.

Since half of the clients seen at the NorWest CHC Diagnostic clinic have no primary care providers, we accept these clients in our clinical practice. These clients typically present in poor health. Our multidisciplinary team includes Physicians, Nurse Practitioners, and access to a psychiatrist for consults. Therapists provide counselling for our clients and their families. One of our Community Health Workers can provide intensive case management for clients referred to the FASD program.

We have trained staff from many organizations such as child protection agencies, youth correctional facilities, policing, community social services, First Nation communities, school boards, and students. They have been provided with 4 days of FASD training in order to become FASD resource people within their organizations. We host a major training event once a year, bringing a FASD expert based on the needs of our community partners.

We offer an 8-week FASD Caregiver Program. This initially began as a parenting program, and was adapted to include partners, friends and family members of individuals with FASD. We are supporting the development of a peer lead support group for adults.

Our FASD Programs are available for individuals who are referred to the NorWest CHCs for diagnostics, as well as means to maintain our life skills expertise with this population. We run a community kitchen every second week featuring a hands on food preparation component and a life skills component. We organize an outing every second month in lieu of a community kitchen to develop social skills covered in the life skills program such as appropriate and safe activities. We are currently piloting a Peer Led Support Group running once a month in the evening, calling up to 30 clients to invite them to the group, with a core 6 participants showing up.

We host a yearly FASD Awareness Day event with the FASD Coalition partners has been held since 2002. At the 2008 FASD Awareness Day event, a live theatre production was launched to increase awareness of social and emotional issues surrounding mothers giving birth to individuals with FASD. For the 2013 FASD Awareness Day event, we partnered with the Liquor Control Board of Ontario (LCBO) for an awareness and media event at its four Thunder Bay locations.

The breakdown in the diagnostic process occurs with delays in access to assessments or when we lose the client. We have several mitigating strategies. The NorWest CHCs has up to 25 points of access via our outreach, and Mobile Health Services. We have a street outreach presence through a partnership for clients with mental health and addiction issues not currently engaged with service providers. Our multidisciplinary team includes Community Health Workers and Therapists, and access to a Psychiatrist for consults.

We have mapped out the current diagnostic process in terms of required time per function per provider, as part of our attempts to secure operational funding.

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The Community Health Centre is the ideal environment in which to conduct FASD diagnostics. The goodness of fit exists since we have Physicians, Nurse Practitioners, Community Health Workers, as well as the infrastructure, such as ECR, OTN, and we do not bill OHIP. Providers need to be backfilled to maintain our funding commitments detailed as number of clients served, and the number of service provider encounters with clients.

We have recently received year end funding to expand out diagnostic team to include 3 Physicians, 5 Nurse Practitioners and a Coordinator and to train this team. The funding allowed us to provide additional supports to expedite the diagnosis for 10 clients, and to organize a 2-day regional training with travel subsidy.

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