

Attachment

GNWT RESPONSE TO MOTION 2-16(5): ADULT DIAGNOSIS OF FETAL ALCOHOL SPECTRUM DISORDER (FASD)**Part 1: That the Government of the Northwest Territories (NWT) establish assessment services for adults who have FASD.**

FASD is an umbrella term which covers several medical diagnoses including: Fetal Alcohol Syndrome (FAS), partial FAS (pFAS), and Alcohol Related Neurodevelopmental Disorder (ARND). The neuropsychological consequences of prenatal alcohol exposure are well documented and include deficits in basic cognitive and executive functioning and serious mental health problems such as debilitating emotional and behavioral disorders and substance abuse problems.

The best focus for FASD is in prevention. Research estimates that the cost of lifelong handling of FASD sufferers is between \$1 million and \$3 million per person. Prevention of FASD is critical. FASD is a cognitive disability; it could be completely eradicated through abstention from alcohol during pregnancy.

No single intervention is likely to eliminate FASD, research indicates that a comprehensive, multi-level approach to FASD prevention based on best practices to support persons with FASD is most effective. An FASD diagnosis alone does not provide an individual with the information necessary to make positive changes to support optimal life-long functioning. Often individuals accessing diagnosis and assessment services are in need of support for housing, employment, parenting and lifestyle counselling and community based supports.

Generally in Canada, an FASD Diagnosis is challenging to achieve and the incidence of assessment can be low. For example, in Alberta, there are twenty-one FASD Diagnostic clinics, where only eight of them are able to offer diagnostic services to adults. Two clinics offer diagnoses on a fee-for-service basis to adults.

In the Northwest Territories (NWT), FASD adult diagnosis would not result in any enhancement of services available to individuals. Formal diagnosis is not required to access services. A diagnosis alone does not provide an individual with the resources necessary to make positive changes in their life or to support optimal functioning. Positive changes and/or support of skills are required in order for clients to achieve optimal functioning. Currently adults with disabilities who are accessing adult specialized resources follow the development and implementation of a personal case management plan. A diagnosis of FASD would not be necessary for a person to be involved in an individualized adult case plan.

Several factors make adult diagnosis difficult. First, is that adult assessment for FASD is very costly. Also, accurate assessment and diagnosis for FASD requires a multi-disciplinary team of skilled professionals with expertise in FASD and experience

working with adult populations to meet Canadian diagnostic criteria set by *Fetal Alcohol Spectrum Disorder: Canadian Guidelines for Diagnosis*. It would be difficult to establish an adult diagnostic team in the NWT as FASD diagnosis in Canada itself is very new and the guidelines and criteria are still in the research and analysis stages.

In the NWT, additional human resources and professional expertise would be required to develop, monitor and evaluate services. It is not uncommon for Disability Specialists, Career Counsellors, Mental Health Providers and Legal Expertise (Crown, Probation Officer, and RCMP) to be involved in adult assessment in order to meet the diverse needs of the individuals. Currently the Department of Health and Social Services (DHSS) does not have the capacity to initiate and establish services for FASD adult diagnosis.

Currently, one private company in Yellowknife called "Life Care Planning" will provide FASD assessments for adults on a fee-for-service basis (\$3,500) based on legal and cognitive impairment specifically for the sole purpose of employment rather than medical diagnosis.

Part 2: That a multidisciplinary team based on the examples of the Territorial Assessment Team or the Child Development Team at Stanton Territorial Hospital be developed to provide these assessment and diagnostic services in the NWT.

The Child Development Team (CDT) within Stanton Territorial Health Authority (STHA) has trained a specialized team to provide FASD diagnoses for children (birth - 16yrs) in the NWT. The team meets every Wednesday to review referrals. The CDT diagnostic assessment includes individual assessment, family conferencing and goal setting and provides resource connections to the child's home community. Follow-up clinics for children are provided with the purpose of reviewing team goals and the development of treatment plans. Clinics will operate approximately once a month. The main work of the team is ongoing therapeutic intervention with children, their families and community team members such as schools and early childhood programs.

The standards for diagnosis of FASD have been set for children in Canada and include factors that are much easier to determine in children as compared to adults. These standards include:

- A history of maternal alcohol consumption during pregnancy.

In adults, the older the person presenting for assessment, the more difficult it is to confirm maternal exposure to alcohol during pregnancy, including frequency and amount consumed while drinking and what kind of alcohol was consumed. The evidence may not be as accurate or in some cases un-known.

- Neurodevelopmental and behavioral characteristics.

In adults, these characteristics may be the result of any number of biological or environmental factors. The on-set of mental illnesses may start showing which could affect day to day functioning. Comparatively, it will be challenging to determine an FASD actual diagnosis when there are other neurodevelopmental and behavioural characteristics that are being assessed.

- Characteristic facial features.

In adults, FASD characteristic facial features may not be as easily determined. Facial structures will change as the person ages and the FASD identifying facial tones will become less noticeable as the person ages.

Part 3: That programs and supports for individuals and families living with FASD be enhanced to be available to NWT residents who need these services.

The NWT already offers access to services and a continuum of services for adults with intellectual and/or developmental disabilities which could include an FASD diagnosis as long as that disability is confirmed by a doctor.

The available services can include: day and work programs, adult respite, employment enhancement programs, group homes and supported living programs. Access to these services can be obtained through the Health and Social Services Authorities. If individual needs are complex and require more intensive supports that may not be available in the NWT a referral for consideration by the out of territory (OOT) placement committee is also an option for specialized services.

NWT adult persons with any disability who are not able to live on their own may qualify for Income Assistance for shelter, food, clothing and utilities along with a disability allowance. Income Assistance for a disabled person in the NWT is provided without the person requiring participation in a “productive choice”.

A number of services are currently available in the NWT for adults with disabilities that may include FASD:

- The Government of the NWT (GNWT) offers hiring priority for persons with disabilities under its Affirmative Action Policy.
- The DHSS supports the NWT Council of Persons with Disabilities offering:
 - Advocacy, support and referral services to persons throughout the NWT; and,
 - Respite services to families of children with disabilities.

The DHSS supports and provides funding to the Health and Social Services Authorities to sustain a number of agency-based programs, including:

- A territorial housing facility for adults with disabilities in Hay River.
- The Case Manager at the Yellowknife Health and Social Services Authority assesses client needs and helps the clients obtain those needs.
- The Yellowknife Association for Community Living (YACL) holds Peer Support Groups once a week for persons affected by FASD.
- YACL offers services for persons with intellectual disabilities seeking employment through its Employability Program.
- YACL has a Skills Training and Community Inclusion program for adults with intellectual disabilities.
- Respite services are available to families of adult persons with disabilities in Yellowknife and Hay River.
- YACL and the YWCA provide specialized housing services in Yellowknife for persons with disabilities.

The DHSS is currently working with the Beaufort Delta Health and Social Services Authority and the Tlicho Community Services Agency to determine if a family living home/adult foster care model of supportive living services is feasible in the NWT. Potentially new clients could then remain in the NWT and other clients who were placed OOT could be moved back to the NWT.

This pilot will potentially alleviate pressure within the acute care and long-term facilities by attempting to keep people in their homes and communities for as long as possible, and will include persons with FASD along with cognitive disabilities.

Part 4: That the government provide a response to the motion within 120 days.

This submission is the formal GNWT response to Motion 2-16(5) that was passed on March 3, 2010.

