

**SYMPOSIUM ON
FETAL ALCOHOL SPECTRUM DISORDER
August 18 – 20, 2005
Dawson City, Yukon**

Introduction

Brad Bell, Manager, Early Childhood and Healthy Families Programs, gave opening remarks and a welcome to the Symposium on Fetal Alcohol Spectrum Disorder. The Canadian Northwest FASD Partnership, Federal Public Health Agency and Yukon Government Department of Health & Social Services sponsored the symposium.

Special thanks was given to the organizing committee:

Rochelle Best	Judy Pakozdy
Sharon Davies	Micki Deuling-Kenyon
Pat Living	David Amirault
Irene Lubbers	Pat Martin
Ruth Borgfjord	Darla Kulych

The symposium will focus on various programs and initiatives regarding FASD that are being provided in other jurisdictions as well as in Yukon. It is hoped the symposium will provide professional development for local, front-line workers.

Opening Remarks

Hon. Peter Jenkins – MLA Klondike, Minister of Health & Social Services

Minister Jenkins acknowledged the Canadian Northwest FASD Partnership and the strong commitment of the Yukon Government to the serious problems surrounding FASD. He noted the progress made to date, and the need to move forward with support for children, families, and communities. The importance of early diagnosis and the valuable work carried out by the diagnostic team was recognized, as well as the need for expanding diagnosis for ages 6 to 21 years, and those in the justice system. Through shared learning we can gain a better understanding of what it takes and how to support those living with FASD.

Hon John Edzerza – MLA McIntyre-Takhini, Minister of Education

Minister Edzerza thanked the Tr'ondek Hwech'in First Nation in Dawson for having the Symposium take place on their traditional lands. Minister Edzerza told of personal experiences, and related a traditional story that focused on seeking understanding, going back to the traditional ways, taking the guilt away that is carried by women, and the important role men played in supporting their women. He stressed the need to change the mindset of the political people to move towards providing programs, such as a special problem solving court that would deal with those suffering from alcohol/drug addictions, FASD and mental health problems. Minister Edzerza also noted the need for special educational programming to support those with FASD.

NOTE: information noted below on each of the sessions is meant to provide an overview of the presentation – it is not a verbatim transcript of the presentation.

DAY 1 – AUGUST 18TH

Plenary Session: Diagnosis – Canadian Guidelines

Dr. Ab Chudley, Winnipeg, Manitoba

Dr. Chudley opened his presentation by providing FASD Learning Objectives.

- Review the classification, etiology, epidemiology, diagnosis and strategies used in prevention
- Identify brain injury patterns resulting from in utero exposure to ethanol
- Identify at risk drinking women, referring suspected affected individuals, and follow-up with community supports
- Review the history, scope and content of the Canadian FASD diagnostic guidelines.

FAS is not a new disease, however it was not until the early 1970's that a pattern of birth defects was defined, and a system devised to evaluate and assess facial features. It was stressed that diagnostic tools cannot be used in isolation - when making a diagnosis one must evaluate growth deficiency, facial features, brain dysfunction and gestational alcohol.

Over the past thirty years the terminology related to FAS has evolved to the present day fetal alcohol spectrum disorder or FASD. FASD is an “umbrella” term that encompasses FAS and partial FAS (pFAS), as well as alcohol related neurodevelopment disorders (ARND). FAS is only the “tip of the iceberg” and the majority of children affected by FASD are invisible.

FAS affects about 1% of our population, and is much higher in some communities. It is estimated that the combined rate of FAS and ARND is at least 9.1/1,000.

What amount of alcohol can cause a problem? The more a pregnant mother drinks, the greater harm will be done. There is no safe amount. Cognition, fine motor coordination, and language skills are affected even at the lowest prenatal alcohol exposure, indicating no threshold of these neurobehavioral outcomes.

Dr. Chudley presented material on the brain and the guidelines surrounding the neurobehavioral assessment. Some common symptoms in infancy include: excessive arousal, sleep problems, short attention, developmental delay, motor abnormalities, abnormalities in tone, reflexes, atypical sensory responsiveness. Common symptoms in school age children can include: attention deficit, impulsivity, hyperactivity, memory problems, behaviour problems, problems with peer friendships and judgement, learning disabilities. Common symptoms in adolescence may include: problems with memory, learning disability - especially language, complex mathematics, impulsivity, problems planning, organization, complex decisions, weak academic achievement, adaptive behaviour problems e.g. emotional, social withdrawal, easily led, poor judgement. It should be noted that IQ does not define FAS.

Individuals with FAS/FAE have a range of secondary disabilities – which could be improved with appropriate interventions. These secondary disabilities can include: mental health problems, disrupted school experience, trouble with the law, confinement, inappropriate sexual behaviour, alcohol and drug problems.

The importance of the role of the primary care physician was highlighted (e.g. screening women at risk, referrals to addictions counselling services, identification of children with facial features and referral to an FASD diagnostic team for evaluation, follow-up management and support and coordination of specialty referrals).

Dr. Chudley then moved on to discuss the FASD Canadian Guidelines for Diagnosis. A brief history on the development of the guidelines was presented. The guidelines consist of seven areas: 1) screening and referral, 2) physical examination and differential diagnosis (growth, facial features, 3) neurobehavioural assessment, 4) treatment and follow-up, 5) maternal alcohol history in pregnancy, 6) diagnostic criteria for FAS, partial FAS and ARND, 7) harmonization of the Institute of Medicine (IOM) and 4-Digit Diagnostic Code approaches. The guidelines were published as a special supplement in the Canadian Medical Association Journal on March 1, 2005, along with an article on Recognizing FASD in primary care practice. This information is also available on the internet.

Current and future challenges regarding the guidelines were discussed. Issues such as use of the guidelines, evaluations, updates, funding and training are challenges that will need to be met now and in the future.

FASD requires a multidisciplinary team for diagnosis. The team may include: physician, psychologist, social worker, teacher, speech pathologist, occupational therapist. A decision will need to be made on who should be referred and the process for a coordinated assessment and follow-up service needs to be in place. Telemedicine may be used in rural and remote areas to reduce the stress on the family of travelling to a larger centre and cut down on travel costs.

The benefits of diagnosis include:

- New way to understand a child's difficulty
- Open doors for service (family support)
- New strategies at home and community places
- Better medical management
- Prevention of secondary disabilities
- Prevention of future alcohol-affected children
- Build a circle of support with respect and understanding

Diagnosis of FASD is not an end in itself. It must be linked to follow-up support and education for the child and family. It is not realistic to think that FASD will be 100% eliminated – it may be realistic to aim for a 10% reduction over 10 years.

Comparison of FASD Diagnostic Team Models of Intervention

Alvin Buckwold Child Development Centre

Dr. Pat Blakely – Saskatchewan

Dr. Blakely gave a presentation on the Alvin Buckwold Child Development Clinic in Saskatoon, Saskatchewan. The clinic was established in the late 1970 and has a clinical database of over 1200 children, with over 800 children being actively followed. This allows for a longitudinal study of children seen at the clinic.

Only children between the ages of 0 – 18 years and referred by a physician are assessed. In addition there must be a confirmed history of prenatal alcohol exposure. Referral sources are from pediatricians, neonatologists, family physicians, pediatricians, and the nurse in charge in nursing stations.

The assessment team is made up of a pediatrician, psychologist, occupational therapist (OT), physical therapist (PT), speech-language pathologist (SLP), social worker, and other professionals as required. Assessments are carried out for children under two years of age, children two to six years, and children over six years. Children under two are usually assessed within two months, and the wait time for children over two years is between nine to twelve months. Follow-up assessments are carried out at 5, 10 and 15 years (transition times). Follow-up on younger children may be as frequent as every three months dependent on need.

Travelling clinics go out to rural communities (at the request of the community) three times per year. Approximately 25 to 40 children are seen over two days. Follow-up, if required, takes place in Saskatoon. The use of telehealth has assisted with assessments in remote communities. Adult and court ordered assessments for FASD are also carried out.

Presentation on Neuropsychological Assessments

Dr. Jo Nanson

Dr. Nanson provided information on neuropsychological assessments carried out to assist in the diagnosis of FASD. The FASD Canadian Guidelines for Diagnosis are followed.

Few children are diagnosed with FASD at birth, rather is it usually their behaviour that creates a problem and they are then referred for assessment. Diagnostic assessment is best used as part of a multidisciplinary team. A medical diagnosis must be obtained from a physician, and families must be involved with any assessment. Any assessment must involve support systems, for both the child and the family. A good psychological assessment will lead to the need for structured, supported programming to assist both the child and the family.

Lakeland Centre for FASD, Cold Lake, Alberta

Joanne Ring

Joanne gave a brief history on the development of the Centre and the process involved in getting the Centre operational. The Centre provides diagnostic and assessment services through multidisciplinary teams.

Two teams provide assessment for children – approximately 160 children have been seen to date, with 100 more on a waiting list, and it is estimated that 1,000 children need to be seen. Anyone can refer a child for assessment, but there must be a connection with the birth mother regarding alcohol use during pregnancy.

There is one assessment team specific to adults, and approximately 30 adults have been seen. Following diagnosis, the team makes recommendations that make sense to the client in their particular community. Support consultants are also available if required.

A mentorship program is in place that provides support for women who are pregnant and continue to drink. This support is available for up to three years.

The challenges faced by the Centre include having informed, trained team members, back up team members, team dynamics, respecting that team members may have family or friends at the Centre, and recognizing the emotional needs of their team members.

The successes of the Centre are managing difficult situations, policy is set as a team, putting families first, working together as a team when making diagnosis and recommendations, and relying on each others skills and expertise.

Mobilizing the Community

Susan Opie

Susan presented a brief history on the Interagency FASD Program in Winnipeg. The program was established in 1994 through a collaborative process with four other agencies in Winnipeg, and is currently funded through the Public Health Agency of Canada and the Community Action Program for Children.

The FASD Program works with families raising FASD children by providing support to families during the diagnostic process, and services following diagnosis, early intervention to children 0-6 years, short-term consultations with families and agencies, and sensory-integration consultation. In addition, the FASD Program provides training and presentations, houses the 1-800 FAS Manitoba phone line, provides a staff person to work on a youth justice pilot project, and conducts pilot project research.

The Program works by transferring knowledge to parents and professionals, provides a family-centred practice with home and community based services, works on a multi-systems collaborative intervention approach, and provides advocacy.

Susan provided practical examples of how intervention is carried out within the Program. This highlighted the need to provide intervention with a non-judgemental approach and to link families and individuals with the appropriate resources available. Intervention must fit for the

individual and their family, and we must recognize that families know their child best – even if the family functioning appears less than “ideal”.

Intervention also means understanding neurological differences and the impact this has on learning, parenting, discipline, teaching, etc. We should be working towards a paradigm shift with family, schools and justice programs. Different expectations would allow for success for all involved. In some instances we need to modify the environment – a more structured environment supports safe and appropriate behaviour. We need to try differently, not harder. At all times we need to be aware of stress – both for the caregiver and the individual with FASD.

Susan noted that assumptions about individuals with FASD can be dangerous and need to be examined. Some common assumptions include: they don't care, they don't want services because they have missed appointments, they understood what you said, they will remember what you said, they need to learn and take responsibility, you are enabling client dependence.

Public Health Agency – Canada's FASD Action Plan

Mary Johnston

Mary provided an overview of the Health Portfolio and the Pan-Canadian FASD Initiative – who was involved and what they do. She likened the work being done on FASD to an airplane – we may all be flying at different levels, but are all aiming for the same goal. While the work undertaken at the federal level may be flying at “35,000 ft”, it is being carried out to support those providing services in the front-lines.

The Health Portfolio consists of the Public Health Agency of Canada, First Nations and Inuit Health Branch, Healthy Environments and Consumer Safety Branch, Health Products and Food Branch, Canadian Centre on Substance Abuse and the Canadian Institute of Health Research. Other federal partners are Public Safety and Emergency Preparedness, Justice, Social Development, Human Resources and Skills Development, and Indian and Northern Affairs.

Mary provided information on what work is being undertaken by various Branches/Agencies within the Health Portfolio.

The national vision of the Public Health Agency – Pan-Canadian FASD Initiative is to prevent FASD and improve outcomes for individuals, families and communities. Public Health activities that support this vision include six areas:

1. Policy Development (e.g. National Alcohol Strategy and Pan-Canadian FASD Strategy)
2. Coordination & Collaboration (e.g. National Advisory Committee on FASD)
3. Identification, Screening, Diagnosis and Monitoring (e.g. FASD: Canadian Guidelines for Diagnosis, follow up training/education for health care providers)
4. Professional Awareness, Education and Training (e.g. National Survey of Health Care Providers, Training and Education Programs)
5. Public Awareness and Education (e.g. Healthy Pregnancy Campaign)
6. Community Capacity Building (e.g. National FASD Strategic Projects Fund)

The First Nations Inuit and Health Branch FASD Program supports a community focused approach that will build and strengthen the foundation for action at the community level. This includes capacity building and testing best practices such as mentorship and multi-disciplinary teams.

The Canadian Institute of Health Research has provided over \$2.9 Million in FASD research over the past 5 years, and in the 2003/04 fiscal year nine projects received nearly \$900,000 in funding.

The Canadian Centre on Substance Abuse is Canada's national addictions agency and maintains an FASD information and consultation service, and serves as the focal point for Canadian practitioners addressing FASD.

DAY 2 – AUGUST 19

Living with FASD – A Parent's Perspective

Cheryl Jackson

Cheryl spoke of their family's trials, triumphs, heartbreak and joy over the past 30 years of raising and living with a son with FASD. She spoke of the need to connect with the communities as early as possible in order to build trust. It is important to be non-judgemental and to provide early education on healthy living and relationships. Trust and respect must be built with mothers, and partners need to take a role in providing and protecting the family.

Not all communities are at the same place - support and assistance in communities needs to be flexible to accommodate all persons needing assistance. A program similar to home/community care would be beneficial. It is important to have a "home-like" supported living arrangement, as opposed to an institutional setting.

Cheryl believes FASD can lead the way to sobriety – it can break the cycle. We need to look for ways to reduce the incidence of FASD. Cheryl stated that she started out suffering, but is now struggling to move forward.

Elementary School Supports

Bev Wahl – Principle, David Livingstone School, Winnipeg, Manitoba

Bev gave a presentation on a school model for children with FASD that included a modified curriculum, classroom design and option of support. She stressed the importance of the strengths of kids, the importance of the school environment and the need to set things up to be successful.

A brief history of the beginning of the program was provided. There was a lobby for support for children transitioning from the preschool program to the school programs. With input from a number of agencies such as the Winnipeg School Division, Child Guidance Clinic, FAS Outreach, Family Services, nursery school staff, etc., the first program started in 1995.

This program started with students spending _ day in kindergarden and _ day in nursery school. Supports such as a speech language pathologist, occupational therapist, teacher assistant, behaviour support and FAS outreach worker were involved with the program. With more children being identified the program was expanded to the elementary school in 1996, and in 2003 a junior high program was introduced. Two schools in the division currently offer programming for FASD students.

Some outcomes of the programming include: increased awareness of FASD, environmental adaptations/teaching strategies, resource materials, trained personnel, clinical support, more programs to meet needs and partnerships.

Bev noted some of the hopes and dreams for the project which include an academic emphasis with recognition of difference and supports, increase the child's ability to function in a less restrictive environment, and adaptations and strategies to teaching.

A review of a CBC video and slides showing classroom activities on a daily basis were presented. In addition, Bev provided handouts and demonstrated a number of supports that assist FASD children with learning in the classroom.

An evaluation process of the programs will be carried out over the next year.

The presentation closed with stories from FASD students, and what it has meant to them to be able to attend the programs.

Child Development Centre – FASD Diagnostic Team

Rochelle Best – CDC Diagnostic Team Coordinator

Rochelle presented an overview of the FASD Diagnostic Team, including members and the diagnostic model used in diagnosis. Rochelle then explained the process involved in obtaining an FASD diagnosis.

Anyone can refer a child between the ages of 18 months to 5 years for diagnosis. However, there must be confirmed exposure by the birth mother to alcohol, and the biological parents and/or caregivers must be in agreement with the referral.

A pre-assessment process then takes place in which background information regarding medical/family/previous interventions/developmental history is obtained. The Coordinator meets with the family to explain the process and provide information on the supports available. The Diagnostic Team meets prior to assessment to determine the assessment strategy, and may also do a home visit or pre-visit to observe the child.

Assessment day includes a medical examination, caregiver interview and developmental assessment. The Diagnostic Team meets to share observations, discuss the diagnosis, review recommendations, and determine how best to present the findings.

Within two days of the assessment, the family meets with members of the Diagnostic Team and a support network to discuss the diagnosis and their recommendations.

Within 24 hours of diagnosis, information relating to the diagnosis is shared with the primary health care provider. With the consent of the caregiver, the Coordinator meets with the CDC team and other agencies that may be involved in the care. A report is then prepared by the Diagnostic Team, which is reviewed by the parents prior to release.

The Diagnostic Team meets with their CDC counterparts to monitor the progress and re-evaluate as required.

The Diagnostic Team is the only team North of 60 and some of their challenges/successes include working in a small community, developing local expertise and the need for on-going education, travelling to rural/remote areas and providing a diagnosis and working with the supports available in small communities.

Rochelle stressed the importance of the referrals meeting the assessment criteria. An assessment cannot be carried out unless there is caregiver consent, the child is under 5 years of age, and there is confirmed exposure to alcohol consumption by the birth mother.

Department of Education – Carmacks Project

Lanie Tourangeau, Heather Alton, and Deb Evansen-Hill

The Carmacks Project is a collaborative project between the Carmacks Little Salmon First Nation, Tantalus School, and the Department of Education to create supports for students with FASD. This is a three year pilot project that is based on collaboration with the community, is school-based, and provides training and support for educators delivering programming to students. It is hoped that this project can be expanded to other communities.

A brief summary of the history of the project and the work undertaken over the past three years was provided. The importance of consulting with the community, school, First Nation and other support agencies, and the need to build trust was emphasized. A FASD Asset Mapping project provided the community the opportunity to see the assets and resources they have available and to feel positive about their community.

Work for 2005/06 is focussing on: a Teacher Resource Manual that will reflect the northern setting and assist teachers to connect with communities and families, a curriculum that will focus on FASD prevention from K-Grade 12, a teacher mentoring project, and a project evaluation.

The successes of this project include an increased awareness of FASD, resource development (teacher training and curriculum development), more student support, teacher training, and a better connection between the community and the teachers.

Challenges of the project identify that change is slow, community capacity can be an issue, the need to reframe how students with FASD are seen by teachers, the need for school and community to work together and how community issues can impact the process.

The key points identified through this project are:

- a community driven approach is essential
- shame/guilt associated with FASD make it difficult for members of the community to get involved in the project
- prevention through education

Yukon Success Stories – Mobilizing the Community

Judy Pakozdy - Fetal Alcohol Syndrome Society of the Yukon (FASSY)

FASSY is a non-government organization that provides services to people with FASD and their families, women at risk of having babies with FASD, and professionals and people who work with FASD.

Judy gave a brief overview of FASSY and the work they are currently doing in providing assistance for adults with FASD. Some supports are available, but they are not adequate, and obtaining secure ongoing funding continues to be a major issue for the Society.

Other issues faced by the FASSY and their clients include limited support workers (currently four workers on call 24/7), no diagnosis for clients and limited supports/counselling, lack of adequate nutrition for clients, no money or time management skills, isolation/loneliness, lack of recreation, need for assistance with transportation, housekeeping and laundry, assistance with child care and parenting.

Mary Amerongen – Options for Independence Society

Mary provided information on the Options for Independence Society which provides housing for individuals with FASD. The residents are referred from FASSY. A building with six apartments provides stable, safe housing and the building has support staff available 15 hours per day.

Clients must be over 18 years of age, be a manageable risk, and be considered low income (follows Yukon Housing Corporation criteria).

The approach taken with clients is to allow them to live as “normal” a life as possible. Supports are available, but are voluntary and their behaviour is their choice except for the standard landlord/tenant rules, and safety/health requirements. A sense of community within the building is encouraged and residents may work closely with their Supported Independent Living worker to achieve cooperation and continuity between the residents’ needs and the community supports available.

Support staff try to provide assistance with life skills, communications, problem solving, hygiene, housekeeping, gardening, etc. In addition, staff provide companionship, employment support, assistance to connect with family, assistance to medical appointments, delivering mail, etc.

The program provides greater stability, less involvement with the justice system, less stress in the resident’s life, less disruption, and the development of somewhat better life skills. There is a sense of trust that is established. The key is to recognize the uniqueness of each individual.

The biggest challenge to the program is to secure adequate funding in order to maintain and hopefully expand the services provided.

Elaine Seier – With a Little Help from My Friends – FASSY

With a Little Help from My Friends is a four years project that received funding through federal Justice Department. The project provides assistance to 16 women between 16 to 35 years of age. Some women have a diagnosis of FASD, but all have a history of victimization and neglect. A coordinator and three part-time staff work with the client, their family and friends to reduce crime and victimization.

Clients are asked what they need help with and staff try to address the greatest safety needs. The women all have issues with trust, anger management, loneliness. Staff provide emotional stability and reduce stress by providing unconditional support, understanding and companionship. Clients need to be believed in, to hear that they are good people and that they have a valuable role to play in the community.

Judy noted that we need to stop being judgmental about these women and have respect for the complexity of the problems they face. We need to have patience and focus on what the client needs.

Panel: Transitioning Through Life

Dale Cheeseman – Youth Achievement Centre

The Youth Achievement Centre provides educational programming within the Youth Justice Branch of Family & Children's Services. The program is for children between the ages of 12 to 17, who have been involved with the criminal justice system, are at risk of offending, or involved with child welfare. There is a classroom at the Young Offender's Facility, and an educational outreach classroom at the Youth Achievement Centre. Youth in the Young Offender's Program are required to attend the classroom. Youth attending the Achievement Centre sign up for classes that meet their needs and/or schedule.

Students attending the Centre often have learning or behaviour difficulties. They do not have a diagnosis of FASD, but many have the FASD profile. Most are out of the public school system, and all are high needs at risk youth.

The goals of the Centre are to assist youth to get into the mainstream schooling, prepare for college or learn lifeskills. The program is unique in that it meets youth where they are at in the education system – each youth is assessed and a program is tailored to meet their needs. The youth identify their goals and what is important to them, and the centre works with the youth to achieve their goals. There is a small class size with 1:3 or 1:1 ratio. The classroom has low stimulation, and youth can work together or alone. Everyone has their individual space.

Not all programs are education based – there is experiential learning and classes in woodworking, carving and pottery are offered. As well recreation activities and information on nutrition is provided.

Staff have an understanding of the youth and the issues they are dealing with and understand there may be times when other issues take precedents. There is a dedicated teacher and program facilitator. Youth are encouraged to take breaks when needed, and staff monitor the stress level of the students.

The program works because of the structure of the classroom, low numbers, safe and supported environment, one to one support, the youth feel they have control and are independent, there is no competition, and they are praised and rewarded for their work.

Rosemary Burns – Elementary to High School

Rosemary provided an overview of the supports in place to assist a student in the transition from elementary to high school. There are three supports available to students – the lifeskills classroom within the school – Riverfront School – provides an educational setting for students with conduct and cognitive impairment, and the Youth Achievement Centre.

The goal is to teach the whole child and to celebrate the uniqueness of that child. Social development, problem solving, accountability and responsibility form part of the curriculum for the child. The special needs of the child must be determined, and an Individualized Education Plan established. While the school believes in an unrestrictive learning environment, organization and structure assist and support the student. Students learn at their own level and engage in work and homework as required.

Rosemary provided information on the process for students transitioning from elementary to high school, and how a student orientation and individual meetings are set up between the child, parents/caregiver and educational staff to ensure a child's special needs are met.

Secondary schools need to let go of some of the requirements for graduation for special needs children. Schools need to be flexible to the needs of the child in order for the child to have greater opportunities in life.

Shirely Watts Hasse – Services for Persons with Disabilities

Shirley provided information on Services for Persons with Disabilities – a newly formed branch of Adult Services. This branch consists of three case managers with a caseload of over 140 persons. Clients have a range of disabilities or multiple disabilities, and referrals are made from a number of areas – self-referral, families, schools, Whitehorse General Hospital, mental health services, Learning Disabilities Association of Yukon, FASSY, Justice, First Nations, College (Essential Skills Program), etc. There is no diagnosis of FASD, but it is suspected in a large number of their clients.

Services for Persons with Disabilities provides a client centered approach. A relationship of trust and positive regard is developed that focuses on success and the need to combine community safety with the individuals' needs. Staff tries to be accessible to their clients maintaining a drop-in schedule for appointments, and also visit in homes, hospital or other settings when necessary.

There are no pre-conceived notions as to where their client is at – collaboration is carried out with case teams/service providers to provide the needed supports. Staff assists with crisis

management and problem solving. Ongoing professional development and continuous education is essential to ensure staff develops a greater capacity to handle their varied caseloads.

Staff has the opportunity to assist clients with their money management when they receive social assistance through the Department. This is done through direct pay for rent and utilities, etc. Clients with severe and prolonged disabilities are also eligible for the Territorial Supplementary Allowance, which was recently increased to \$250/month. First Nations and DIAND also have a similar program.

Case managers assist with the coordination of assessments, referrals and linking to other services (e.g. Yukon College – Essential Skills Programs, Learning Disabilities Association of Yukon, Yukon Learn, Supported Independent Living). Respite funding is provided to families for appropriate and safe respite, and contracts may be established to assist those with services not available through the regular service providers.

DAY 3 – AUGUST 20

Building Capacity for Support

Barb Durbin and Linda Schmidt, College of New Caledonia, Burns Lake

Barb and Linda provided information on the Focus Employment Program that takes place in the College of New Caledonia in Burns Lake. The Program was established for FASD students who were interested in gaining employment, and is focused on developing elementary job level skills which use alternative learning strategies specifically designed for adults with FASD. No diagnosis of FASD is needed – participants self-identify, and are not required to leave the program after any set time. Students feel an ownership in the Program and it is important for them to feel a part of the College and the community.

A brief history of how the program got started was presented followed by a video, that was prepared by the students in the Focus Employment Program, and provided information on the types of supports and programming offered through the College.

The Program does have modifications such as having staff available through Christmas and spring break, part-time employment in the summer, and a highly structured classroom. Students take part in volunteer activities, job readiness training, catering, computer assisted reading, and practical math. Additional assistance/services that would benefit the students are supports such as financial aid, parenting skills, disability, securing adequate housing, managing utility costs, navigating the justice/parole system, and managing medical needs.

The success of the Program can be measured by the continued support and advocacy for FASD individuals, better understanding of the students within in the College, redefining success by accepting the students disabilities, improved self-esteem, reduced depression, high attendance and respect of the students.

The College is able to provide many supports to the students – counselling, day care, early intervention, family centred programming, lunch programs, #1 Dad's program, and the Business

Action Service Employment (BASE) Program which assists in securing employment for the students.

The Program works towards fostering community understanding and support. Students participate in community events, and provide assistance such as catering, craft sales, mowing lawns, painting, etc). Ongoing, constant support is required 24/7 in order to make these activities a success.

Change is made slowly, however, goals for the future include increased student involvement with BASE, computer assisted learning and increased advocacy for more services for the disabled.

Panel: Supportive Living Options

Thomas Gibb – Mountain Ridge

Mountain Ridge is a four bed, long-stay home for male youth 13 to 18 years of age who have been identified with sexually intrusive behaviours. All youth are in the care of Family & Children's Services and have been referred by them to the home. Mountain Ridge has been in place for 9 years, and in 1999 treatment services were started. The home offers supervision, support and treatment.

The goals are to ensure community safety and the growth and development of the youth. Mountain Ridge tries to create a "home-like" atmosphere as much as possible by involving the youth with setting rules, meals, activities, attending school/jobs, and interacting with their peers and the community (e.g. Special Olympics).

Areas of opportunities and challenges are presented in the day-to-day running of the home. Mutual respect and secure attachments allow for the growth and success of the youth. It is important to believe in the potential of each individual.

Dr. Jereme Baumbach – Mountain Ridge

Dr. Baumbach provides treatment services for the youth at Mountain Ridge. He provided a brief summary of the early findings on the outcomes of the treatment. Dr. Baumbach noted that 11 youth have gone through or are in the program – of this number 7 have been discharged. 6 individuals have had a diagnosis of FASD, and all have had sexual offences.

Conclusions drawn from the statistics available would indicate that deviant sexual interest at discharge is a powerful predictor to future offending, and that the treatment program for the youth is assisting in the reduction of deviant sexual behaviours upon discharge. There is also an indication that the severity of the offences is reduced by support and supervision. Dr. Baumach noted that care must be taken when reporting statistics for the program due to the small number of clients and the short timeframe the program has been in existence.

Nancy Dussener & Guy Coderre – Residential Youth Treatment Services

Nancy and Guy provided information on Residential Youth Treatment Services (RYTS), the challenges they have faced, and their vision for future services.

Originally RYTS was set up to provide assessment and treatment to youth in a family-focused environment. There was no diagnosis of youth that may have FASD, and therefore no programming geared to their needs. The youth were disruptive to the programs and staff felt overwhelmed and discouraged by the lack of success.

There was a process of discovery in which some youth were identified that seemed to have an inability to “get on track”, could not plan or follow-through with instructions, were easily distracted, attracted to street life, and displayed deviant behaviours. At the time, there was also no consensus among professionals as to what was an FASD presentation. The services provided were overshooting the child’s abilities, and many youth did not want to be identified as FASD, and refused to take part in the programs provided.

Nancy and Guy set out their vision of optimal service elements for RYTS. This would include such services as:

- Early assessment - by a multidisciplinary team, and more consistent placement
- Multidisciplinary treatment – teamwork in setting out short and long term planning, providing a complete picture of the child, not overwhelming the child but providing more consistency across time
- Independence – connections to an individual worker within a service, long term goals set out, recognition of the communities ability to work with FASD, responsiveness to the concerns of caregivers regarding difficult behaviour, and working “with” not “for” FASD youth
- Education – ongoing assessment, IEP’s that reduce frustration, and support services that are flexible and readily available, mentoring
- Residential Support – skilled staff in a small “home-like” setting with mentors to assist youth
- Judiciary – recognition of FASD youth, speed up the judicial process, supports for youth on the streets, and a process for sharing information
- Community Inclusion – mentorship, individual supports, specialized sports programs, life skill programs
- Employment – different options, various volunteer programs, preparation for work, guidance for youth and the employer, mentorship
- Bridging – constant physical presence to guide change and minimize the risk from poor impulse control

Linda Priestley – Respite Care

Linda advised that there is not a lot of research currently available regarding FASD and respite services, however it is well recognized that parents/caregivers of FASD children need respite, and that these parents/caregivers are currently underrepresented in the current respite program.

Respite services can be accessed through Family & Children’s Services – in Whitehorse this would be thorough the intake team; in the communities it would be through the social worker. Respite is available to all children with special needs under 18 years of age – no diagnosis is necessary, just the verification of special needs. The rate and number of days of respite is set depending on the situation.

A financial subsidy may be available. In some instances the family identifies the caregiver and if they are over 19 years of age, and not residing in the household, money will be paid to the family to hire the caregiver directly. Block funding may also be available, so the family is able to use

the funding to use caregiver services when needed. Family & Children's Services have respite home agreements with approved caregivers. If possible, the same caregivers are used for FASD children in order to maintain familiarity for the child.

In order to provide the parents/caregivers with a complete break, respite services may also be available for other children in the family.

Linda noted that there appears to be a lack of awareness of the respite services available, and encouraged participants at the symposium to let parents/caregivers of FASD children know of the respite service.

Donna Wilkinson – Foster Care

Donna provided information on the Foster Care Program. Foster care is run as a separate program in Whitehorse, and through the social worker in the communities. In Whitehorse a seven person team provide assistance to the foster parents as well as the children. A 27 hour training program for foster parents, although not mandatory, is encouraged. Currently most foster homes have one parent that has taken the training.

Patience and communication are key to fostering children. It is important to work as a team with the child as the focus.

Marg Render – Adult Residential Services Program

Marg advised that the Adult Residential Services Program is a component of the Social Services Branch. Residential Services provides a wide range of services to their clients. Client eligibility is not determined by diagnosis or IQ, but rather by functional ability.

In the last several years a number of clients have been repatriated to the Yukon. These were individuals who had been placed outside the Yukon because there was no accommodation or supports available to them. These individuals are now back in the Yukon living in supported living accommodation, and have reconnected with their families and the community.

Adult Residential Services currently has five staffed residences that are rented by their clients. Yukon Government contracts with individuals to manage these homes. There are also approved private homes, similar to the foster home model, that offer suites where a client has a sense of independent living, but support is nearby. The private homes also provide the opportunity for short term life skills assessments for the clients and respite for caregivers.

Some clients graduate from a more structured living arrangement into the Supported Independent Living program. This program assesses the strengths and needs of the client as well as their ability to develop the skills, behaviours and attitudes required to live in the least restrictive environment.

Referrals to the Adult Residential Services Program come from within the department – the individual must be a client of Adult Services.

Janet Vandermeer – Balsam Residence

Balsam Residence opened in 1999 in response to a need for individuals who would be over 18 years of age and leaving the care of Family & Children's Services. A home was required to meet their needs.

The residence opened with accommodation for four male residents. The residents are welcome to stay for as long as is needed and 24/7 support is provided. An elder lives on site and approximately 14 staff members provide assistance. The residence provides a home-like setting.

The needs of the men are listened to – no judgement is passed – and the focus is on today. Some men have been brought back to their First Nation to gain acceptance and understanding. Families, First Nations and agencies such as Victim Services and Special Olympics provide support.

The men learn daily living skills and the elder operates a circle to provide the men the opportunity to share and talk about their concerns.

Consistent staff, continual training and a positive attitude contribute to the success of Balsam Residence.

Panel: Justice Issues - Exploring Justice Options and Transitioning from the Justice Program Back into the Community

Hazel Bergen – Enviro – Wilderness School – FASD Collaborative Project – Calgary, AB

Hazel provided information on the Enviro FASD Reintegration Collaborative Project. This was a three year pilot project which was funded through the Youth Justice Renewal Fund.

The goals of the project were to assist FASD youth that were involved with the youth justice system to reintegrate back into the community and to reduce recidivism. Support for the youth and their families were provided in accessing appropriate community resources. Healthy day programming comprised of school, work and leisure activities was combined with a stable living environment. Assistance to caregivers was provided so they may better understand the strengths and limitations of the young person.

Challenges faced by the project were ensuring that youth had a proper diagnosis, obtaining appropriate staff for the project and working with the community on supports needed by the youth.

Successes of the project were that some stable environments were established, stronger family ties developed, and diagnostic investigation of abilities sessions where everyone involved with the youth was working together for the best interests of the child.

Susan Opie – Manitoba Interagency Committee

The new Youth Criminal Justice Act led to a pre-sentencing pilot program. In 2003 Judges in Manitoba were concerned that FASD youth were not receiving the supports needed. This led to the creation of a steering committee comprised of representatives from various agencies (e.g. justice, interagency, children's hospital, police) who identified a continuum of needs and gaps in services and children who had missed primary and secondary prevention programs – kids who

had “fallen through the cracks”. Initially funding was obtained for 6 months, but has been extended for an additional year.

The goals of the program were to provide diagnosis and referrals for FASD affected youth. Referrals were accepted from justice, other service providers, parents/caregivers. A screening process was carried out with specific criteria. Youth had to agree to the assessment for a court ordered FASD assessment.

The process involved a multidisciplinary team assessment followed by a family debriefing. A court order was prepared and submitted, and a judicial conference was held when required. (The continued education of lawyers, social workers, etc. on FASD is needed.) The sentencing of the youth then took place. Community reintegration, planning, and referrals to the appropriate community resources for support and advocacy were determined. Community development and facilitation of FASD education needs to be part of the process.

Lessons learned from this pilot project identified that the start-up period was critical – short notice of funding made it difficult to get the program started within the prescribed timeframe, differences in approaches and professional ethics need to be acknowledged, other youth could benefit from the project, but could not be accommodated, early intervention services are critical, the need for FASD friendly community programs and services, and that learning continues on a daily basis – the project is a “work in progress”.

Danya Gaudet & Sharon Davies – Restorative Justice Conferencing

Danya and Sharon provided a joint presentation on Restorative Justice Conferencing. By the time youth are “into the system” they may be facing many issues such as drug/alcohol addiction, school drop-out, breaking the law. Youth with FASD may be impulsive and cannot connect behaviour to consequences. If a youth has a physical or visible disability it may be easier to obtain resources, but for FASD youth their disabilities are most often not physically visible. There needs to be more education and communication within the court system and the community on FASD. The safety of the community must be balanced with the needs of the victim and the needs of the youth.

There has been positive growth over the past few years. Workers and case managers have gained more education in FASD and are working more effectively with stakeholders. The Youth Criminal Justice Act is more flexible in looking at the individual needs of the youth and allowing for special considerations.

Yukon has a Youth Justice Panel that is comprised of 15 different agencies. Each stakeholder has input and they work to determine what other options are available as opposed to custody. Judges and lawyers have become more proactive in providing court orders that are written in plain language making it easier for youth to understand.

Challenges include the length of time from arrest to trial – by the time the offence is being tried, the FASD youth will very likely have forgotten what it was even about. Youth may also become comfortable in the custody system. It is a difficult transition from the youth to adult justice system.

Restorative justice conferencing offers a community justice forum where the victim and offender come together to repair the damage. It is of benefit to an FASD youth in that it is very structured, the same language and script are used. Everyone is in the conference that you may need or that may be able to assist. Discussion takes place on how to repair the harm, and how to prevent it from happening again. The process is non-judgmental and not bound by legal boundaries. An education process takes place through the conferencing and a support system can be established. It may not be perfect, but it seems to work best for FASD youth and there are better outcomes for all involved.

Dorothy Reid – Federal Corrections

Dorothy told of her personal experience in raising two sons with FASD.

She outlined what will not work when dealing with FASD individuals:

- Being insensitive to FASD/brain injuries
- Thinking the individuals must be held accountable
- Excluding parents/caregivers
- No diagnosis or communication of diagnosis
- Incarceration as a deterrent
- Overworked parole/probation officers
- Incarceration with a more antisocial/violent peer group
- Isolated interventions with no follow up
- Overprescription of “programs”
- Release without proper support/structure
- Jurisdictional battles (not my problem or area – justice/education/social services)

What would help when dealing with FASD individual could include:

- Diagnosis prior to involvement
- Early structured release
- Support on release
- Advocate for individuals
- Minimal conditions
- Quick turn around of temporary detention
- Community based/relationship based supports
- Education of police, judges, parole/probation officers
- Supports for staff (staff burnout)

Dorothy gave an overview of the Pacific Institutional Regional Treatment Centre, the services offered and the strategies used. However, she concluded by saying that prison is not the environment for those with FASD – and all interventions will not work. What is needed is early diagnosis, appropriate interventions, options for gainful activities, annual income, supported housing, an advocacy system that is funding nationally, but located in the community, and the need to invest in children with FASD from conception to death – this will cost less in the long run.

Wrap Up – Lessons Learned

Judy Pakozdy

Judy summarized the lessons learned over the past three days:

- diagnosis and assessment are critical – diagnosis is also a major prevention tool – 50% of babies with FASD have Moms with FASD
- need to include families in discussions/supports for FASD family member
- lack of services in the rural communities – what services we have are mainly located in Whitehorse
- need for specialized services/programs in the justice and education system
- there have been some successes, and things have improved, but there is still a great need for supports for FASD in Yukon.
- government/NGO's/agencies need to get together to share information and plan for future.

The next steps to move forward with include:

- diagnosis for all age groups in order to get the needed supports
- people with FASD need to learn about their disability
- need to work with all community members and those delivering the services – not just professionals
- need to explore options to deliver services
- need collaboration and communication with all community members
- need to remember that there are many definitions of “success”.

The organizing committee would like to say a special thank you to all the presenters and participants of the symposium for their patience and flexibility. Due to weather conditions it was impossible to fly into Dawson City as scheduled, and the start of the conference was delayed. This meant a re-juggling of the agenda - some presentations were condensed, and the opportunity for a question and answer period was limited. Despite these challenges, the symposium carried on, and provided much valuable information and the opportunity to meet and network with various individuals. Thank you for making the 2005 Canadian Northwest FASD Partnership Symposium in Dawson City a success.