From: Ron Tizzard
To: Pam Rodgers
Date: 11/30/00 1:51PM
Subject: Call to Katherine Owen and Peter McGregor

Hi Pam, I'll use your address as a channel to the group. You can copy if you don't mind

12:20 p.m., just completed a lengthy speaker call to both Katherine and Peter.

Both of them have been on the phones contacting whomever they were able re: development of a human resource bank. Katherine on the Social Service end and Peter on the Detox/treatment end.

Katherine - she has been in touch with people/services pretty well within the provinces of N.S. and N.B..

Peter - has been doing likewise across Canada, concentrating on their detox and treatment resources.

Katherine and Peter asked questions for which there are no answers to this point (as I understand from my attendance at the meeting this a.m.). But, they understood. However, their contacts were asking them the same questions.

I reassured them that answers would be forthcoming as soon as decisions are made re: anticipated dates the assessment team would be going to Davis; anticipated dates identified youth may be moved; the services, more specifically they were being asked to provide etc., logistical questions for which there are few questions right at this moment.

I shared - it is anticipated that the youth et.al., will be brought to the Island, several sights being considered; small team, primarily medical/social workers will go to Davis to do quick assessment, make decisions and move the youth who need to be moved; numbers very speculative; detox will happen with youth in same general area to make best use of resources and medical facilities; then attempt to reduce size of youth groups by using alternate housing etc..

I suggested to Peter that potential staff with Inhalant detox experience quite likely will not be required in Davis, but maybe as consultants on the Island for the first week or so. If sufficient numbers, also maybe to supplement staff monitoring the youth.

Peter has been in touch with a number of treatment programs who are open to helping take youth where vacancies exist. But, many of these programs are now closing for the Christmas break, to reopen in the new year. They need answers in the next few days to negotiate with their staff, perhaps to remain open. However, some of these staff may be open to travelling to the Island during the break, if asked.

I reassured Peter that answers will be forthcoming ASAP..

...Ron...

Works Cited

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2. IOM-Institutes of Medicine (U.S.) Division of Biobehavioural Sciences and Mental Disorders. Committee to Study Fetal Alcohol Syndrome. Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention and Treatment K. Stratton, et al. eds. National Academy Press, Washington, D.C. (1996)

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5. Abel E.L. An Update on Incidence of FAS: FAS is not an Equal Opportunity Birth Defect. Neurotoxicology and Teratology 17(4):437-443 (1995)

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10. Abel: 439

11. "Fetal Alcohol Syndrome: An Issue of Child and Family Health," Policy discussion paper. Canadian Centre on Substance Abuse National Working Group on Policy. Sept. 1994.p.4

12. Fetal Alcohol Syndrome: From Awareness to Prevention. Government Response to the Fifth Report of the Standing Committee of The House of Commons on Health and Welfare, Social Affairs, Seniors and the Status of Women. Dec. 1992. p.7

Mushuau Innu Band Council

Mushuau Innu Band Council

Phone: 709-478-8827
FAX: 709-478-8866
email:

Deanne Case
400

Facsimile

To: Deanne Case
@Fax: 709-729-4009
From: Edgar Branton
Date: Thursday, November 30, 2000 @ 2:44PM
Re: Community Monitors
Pages: 1, including this

Deanne,

The arrangement that we would normally put in place in a case like this is as follows:
We would submit a proposal together with a budget and when accepted a funding arrangement would be put in place outlining the payment arrangements. Funds would normally be advanced to us on a monthly basis. At the end of the project, a financial report would be prepared by us and together with the necessary support would be sent to your department.

These funds would be subject to audit at the end of our fiscal year by our external auditors.

The budget for this particular project is $139,860 made up as follows:

1) 10 monitors that work 10 hours per day for 7 days per week For 12 weeks at $15.00 per hour	$126,000
2) Mandatory employer cost est at 11 %	13,860

Our preference is that we pay our own people and if you are agreeable we can use one of the following options:

1) Advance on a weekly basis: 12 payments of $11,655
2) Advance on a monthly basis: 3 payments of $ 46,620

We maintain our records in accordance with generally accepted accounting principles and would agree for the project to be subject to audit by your dept if you thought it was necessary.

Thank you for your consideration.

Sincerely,

[redacted]

Edgar Branton

Beverley Clarke - Davis Inlet

From: <Al_Garman@hc-sc.gc.ca>
To: <Ian_Potter@hc-sc.gc.ca>
Date: 11/29/00 11:37 AM
Subject: Davis Inlet
CC: <Catherine_Adam@hc-sc.gc.ca>, <GrayI@inac.gc.ca>, <bclarke@mail.gov.nf.ca>, <Katharine_Owen@hc-sc.gc.ca>, <Peter_McGregor@hc-sc.gc.ca>

I just spoke with Chief Tshakapesh; Gerry Kerr and Luke Rick were also on the line. They have agreed to meet with us on Dec. 6 in Davis Inlet. They agree that we need to talk about at least two key items: the immediate crisis response and the long-term healing plan. They would be interested in hearing our thoughts on crisis response - I suggested that we could lay out the model we are using in Sheshatshui. From what they said it is not clear but they appear to be trying to establish their own crisis plan using external advisors they have brought into the community. Regardless, they are adamant that whatever is ultimately agreed it must reflect the unique needs of that community. The Chief promised to get back to me later today and, at my request, I was also told I would receive information on what they are thinking in advance of the meeting to allow government officials to prepare themselves. During the discussion I took the opportunity to reinforce that if they expect governments to pick up the tab, then officials must be involved in decision-making. They had no problem with this. I also highlighted that if the situation becomes such that provincial child protection legislation is invoked, then certain processes begin to unfold with no discretion, ie. apprehension of the children. They understood this as well.

From: Pamela Rodgers
To: Clarke, Beverley
Date: 11/29/00 8:17PM
Subject: room bookings and attached

Bev - we have the collective bargaining room booked from 1:30 onward Thursday for our meetings re: Davis Inlet and, a room booked from 9-5pm at Hotel Nfld for Friday.

Also, I've drafted a list of considerations for internal discussions re: planning for the children of Davis Inlet (attached) and would appreciate any feedback you can give.

CC: Hughes, David

Planning for Davis Inlet children/youth who are gas sniffing

Draft for Internal Discussions

1. How many children? (Names and ages) - List to be faxed or brought by the Band
2. Consents from families:
   - what is required under CYFS Act? who does the work to get the consents? (team of social workers to be identified within the region, across province and across Canada...)
   - what happens if families are not supportive of moving their child from Davis Inlet?
3. Groups of children to be determined according to number of locations identified (most likely unable to place entire group in one location)
4. How, logistically, do we move a large number of children from Davis Inlet (air charters? escorts? buses upon landing...)
5. Assessments/plans for children/families:
   - what is required under CYFS Act? who will do this work?
6. Identify potential locations for the short term (detox) - *currently exploring options*
   - what must be done to get the facilities ready? how long will it take?
   - what is needed for support in each location:
   - medical support
   - methods to maintain contact with their families
   - clothing?
   - provisions for food
   - activities for children - Recreation
   - one-on-one support staff around the clock -
   (how many can be identified quickly? from where?)
   - scheduling/supervision of support staff
   - coordination role
7. Identify placement options following detox:
   - within their own family
   - with relatives
   - foster families (existing or new)
   - in-country
   - other (eg: individualized living arrangements)
8. Identify treatment options
   - CJAY Restoration Center
   - out-of-province treatment
   - family treatment programs

potential locations for detox
- Former Women's Correctional Center, Stephenville
- Former Grace Hospital
- nurses residence, Grace hospital
- military bases: Stephenville, Gander, St. John's, Greenwood
- new Janeway

- NLHC in Stephenville
- Tim Horton's Foundation
- Salvation Army
- Max Simm's camp
- Hockey camp in Stephenville

PROPOSED ITINERARY
November 26, 2000
Goose Bay

8:00 a.m.	Depart St. John's (Pal Hangar #4) to Gander
8:30 a.m.	Depart Gander to Goose Bay
9:30 a.m.	Arrive Goose Bay
10:00 a.m.	Internal meeting (Aurora Hotel - 2nd Fl.)
1:00 p.m.	Meeting with Innu (Aurora Hotel - 2nd Fl.)
5:00 p.m.	Depart Goose Bay to Gander
6:00 p.m.	Depart Gander to St. John's

Arrangements for 2 cars - Tilden (Goose Bay) (Cell # 896-1072)

Aurora (confirmation #01455)

Air Services (729-3092)

Judy Vickers will call if problem with cars

Sheshatshiu Innu Band Council

P.O. Box 160
Sheshatshiu, Labrador
A0P 1M0

Bus: (709) 497-8522
Fax: (709) 497-8757

CODE # 2000-11-146
C.C. 1. RG 4. ____
2. DF 5. ____
3. BC 6. ____
REGISTRY ✓

November 15, 2000

Ethel Starblanket
District Manager
Child, Youth and Family Services
Sheshatshiu District Office
Sheshatshiu, Labrador
A0P 1M0

Dear Ms. Starblanket,

At the Sheshatshiu Interagency Working Group meeting this morning, the community agencies unanimously directed that in Sheshatshiu, Child Youth and Family Services carry out its mandate for child welfare apprehension of children in critical need of protection, including those children who continue to abuse solvents.

It is the strong belief of all the community agencies that the safety of these children is the paramount issue. We cannot continue to tolerate the ongoing neglect of these children by their legal caregivers and action is past due. The ongoing situation is drastic and we need to take drastic measures.

We insist these children be taking into care immediately and that safe placements be arranged for them. We understand that in the short term, the children may have to be placed away from the community and we support this as an essential measure to ensure their safety. We will use the collective community resources to work with their care givers to support them to undertake the work they need to do to be able to resume healthier parenting.

I am asking for an emergency meeting with you before the end of the workday, this Friday, November 17th to discuss this more fully.

Sincerely,

Chief Paul Rich
Sheshatshiu Innu Band Council

Cc: Boyd Rowe, CEO, Health Labrador Corporation
Roger Grimes, Minister of Health
Kelvin Parsons, Minister of Justice
Peter Penashue, President, Innu Nation

NOV 15 2000
OFFICE OF MINISTER

FAX Transmission

Department of Health and Community services
Ronald Tizzard - Addictions Programs Consultant
P.O. Box 8700, St. John's, Newfoundland, A1B 4J6
(709) 729-0719; fax-(709) 729-5824
rtizzard@mail.gov.nf.ca

URGENT

To: ADDICTIONS SERVICES REGIONAL DIRECTORS
Fax: 738-4920; 738-4985; (709) 466-6330; (709) 651-3645; (709) 634-0160; (709) 454-2052; (709) 896-4900;

Date: November 20, 2000

Re: Sheshatasiu

You are all aware , by now I would think, of the extreme situation in this community. Bev. Clarke's office is leading discussions toward a reasonable and durable resolution to the current events.

The Goose Bay Addictions Services office is taking the lead with clinical addictions services in the area i.e. working with the Innu community leaders et. al.. This is a full time preoccupation for that staff at this time, and may be for a few weeks to come.

Would you review and canvass your clinical staff with a view to asking for volunteers, **if they can be spared and are interested,** to spend some time in Goose Bay (short term), primarily tasked to take care of the clinical needs of that office while Goose Bay staff are freed up to assist with the immediate needs of the Sheshatasiu community.

When and if volunteers would be used is unknown to this point, we are in the process of checking potential resources and being prepared should the occasion arise.

You are asked to do this immediately and respond to me. If some staff are interested in participating, please try to indicate when they might be available.

This is much appreciated, and I wait to hear from you. You can fax, phone or e-mail. Thank you.

...Ron....

[redacted]

Health Labrador Corporation
ADDICTIONS/MENTAL HEALTH
DEPARTMENT
Labrador Health Center
Station A
Happy Valley-Goose Bay
Labrador, NF
A0P 1S0

FACSIMILE

CONFIDENTIALITY CAUTION

TO: Delia FROM: Michelle

FAX #: 729 - 0121 DATE: Nov. 20, 2000

NUMBER OF PAGES (INCLUDING THIS PAGE): 5

COMMENTS:

FAX NUMBER: (709)896-4900
PHONE NUMBER: (709) 897-2343

IF PAGES ARE NOT RECEIVED, PLEASE CONTACT THE ABOVE AT(709) 896-5303 AS SOON AS POSSIBLE.

729-0121

STAGE ONE

CRISIS INTERVENTION

a) ASSESSMENT & REFERRAL

Children & youth currently sniffing gas in the community of Sheshatshit to receive
professional assessment through CY&F Services to determine extent of CHILD
protection issues

(Team of social workers in CY&F Services to work in conjunction with community resource workers)

b) 24 HOUR SECURITY TEAM

- CY&F Services providing funds to support rehiring of Douglas Ashini to head up
Team of community members for night patrol in Sheshatshit - Douglas given authority by Paul Rich to hire team of workers for project (total of 10) - to remain in place until at risk youth & children apprehended by CY&F - referrals completed - RCMP presence
- food, drinks to be provided for youth meeting in Innuauishitun

c) CUSTODIAL CARE

- After completion of assessments, CY&F Services will apprehend children determined to be in need of protection. If services not available in province, outside resources to be utilized for DETOX purposes and SECURE facilities to provide basic care and support to children temporarily in care of protective services

* * *

Interim custiodial orders of children in need of protection are designed to meet IMMEDIATE & CRITICAL NEEDS ONLY -
long range treatment programs to be provided through local agencies of Charles J Andrew Youth Restoration Center in Sheshatshit in partnership with Innuauishitun and other locall agencies of the Interagency Working Committee

CRISIS INTERVENTION FOR PARENTS OF YOUTH IN CUSTODIAL CARE / COMMUNITY MEMBERS

Highly recommended that parents whose children have been placed in custodial care (especially those whose children are out of province) receive IMMEDIATE care for trauma associated with crisis Peter Pennashue to meet with Dr Barry, (aforementioned psychologist), to provide services and direction for BOTH parents & community members in need of professional assistance (possibly assessments of those at risk of suicide) AND community caregivers experiencing ongoing stress-related issues

Plans to implement an immediate treatment program for parents to be negotiated with Innu Nation, MCC Labrador, Sheshatshit Band Council, and goverment partners - Bill Stevenson, Regional Representative of Mennonite Central Committee for Labrador/Newfoundland to investigate potential for immediate purchase of facility in Labrador for ongoing treatment of parents affected by alcohol abuse and gas sniffing, reintegration of families and support for ongoing issues of recovery

Program for parents/ local staffing/ training issues currently being evaluated

2) PLAN OF CARE - INITIAL TREATMENT

a) CHILDREN & YOUTH

Children assessed to be candidates for local treatment will be admitted to the Charles J Andrew Youth Treatment Center for a minimum period of SIX MONTHS

It is anticipated that brief, supervised family visits will be arranged for parents and children who are themselves in treatment during this period

* * * The current program is designed for TWELVE residental placements. It is suggested that this program of 24 hour care be provided for those assessed as 'high risk' clients. Alternate local placements for less severely addicted youth will need to be arranged with local CY&F Services. At present all clients are admitted only a voluntary basis only. This has created seriouc problems for staff as they exercise no authority to hold children against their will.

ALL PARTIES RECOMMEND THAT CHILDREN ADMITTED TO THE CHARLES J ANDREW YOUTH RESTORATION CENTER BE IN THE CARE AND CUSTODY OF LOCAL CHILD,

YOUTH & FAMILY SERVICES. This mandates children exhibiting destructive behaviors to remain in treatment for a defined period of time.

b) FAMILY PROGRAM * * * (Initial Phase Only)* * *

Parents (or designated guardians) of children and youth in care will be encouraged to participate in a six week residential program of treatment focusing on issues of alcohol/substance abuse in their own life.

Short term plans regarding the location of the program are being negotiated. Long range plans will call for a permanent facililty for ongoing treatment programs.

* * * It is strongly recommended that a significant portion of the treatment programs for Innu include land based programs (nutshimit)* * *

3) POST TREATMENT CARE:

Following the inital six week residential treatment program adult participants will be offered a day care program of ongoing treatment in the communitiy of Sheshatshit. Participants will be encouraged to continue in the program as part of the anticipated family reintegration process. The suggested length of participation in this phase of the program is a minimum of SIX MONTHS.

Essential components of the program will include native parenting skills training; couples therapy; AA supports groups; ALANON; ALATEEN, GA (Gambler Anonymous); Adult Survivors of Early Childhood Sexual Abuse; Peaceable Homes (for batterers); financial counselling etc. Joint sessions with parents and children in the Youth Restoration Centre where appropriate.(eg joint family counselling sessions; communication skills sessions; anger management; recreational activities etc)

3) AFTER CARE / COMMUNITY SUPPORTS - RECOVERY & MAINTENANCE

LONG TERM COMMUNITY GOALS

It is recommended that a Family, Youth & Community Center be established in Sheshashit with the mandate to develop and offer community members ongoing programs of holistic care. Suggestions of potential programs were initiated by adult participants of the Family Treatment Program

2000, who have successfully maintained their sobriety and have had their children returned to their care by CY&F Services. These include:

Family Nights - family movies; games; music; weiner roasts; storytelling; crafts etc
ongoing AA, ALANON; ALATEEN; ACOA; NA; GA; etc
cooking classes
sewing classes
traditional arts & crafts
story telling
potluck suppers

Future Goals; Sports Plex & Arena in Sheshatshit
Youth Drop In Center
Local van & driver
Preventive Health Care
Career Planning Resources for Aboriginal Peoples

FORECASTED NEEDS ASSESSMENT

Permanent facility condusive to family treatment programming on a year round basis
Training dollars and resources to improve and expand skills of current community workers- (NNECHI: Brentwood)
Access to culturally sensitive educators for counselors working in family treatment
Availability of detox facility where pertinent
Local facility for treatment of ongoing community issues
Co-ordinator of Family Treatment Program
Co-ordinator of Post Care programming in community
Increased budget and program of recreational activities
Programming dollars for program development and implementation

Sheshatshiu Innu Band Council

P.O. Box 160
Sheshatshiu, Labrador
A0P 1M0

Bus: (709) 497-8522
Fax: (709) 497-8757

NOV 24 2000
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Office of the Premier
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November 23, 2000

BY FACSIMILE

The Honourable Robert Nault
Minister of Indian and Northern Affairs Canada

The Honourable Allan Rock
Minister of Health

The Honourable Beaton Tulk
Premier of Newfoundland and Labrador

Dear Sirs,

Further to our conversations with Deputy Minister Shirley Serafini, please find attached a proposed outline of services and resources that we feel would begin to address our most urgent immediate and long-term needs.

Our present resources for detailing our needs in a more formal way are simply overwhelmed with dealing with this current crisis situation of our children.

An immediate response to this proposed outline is anticipated.

Sincerely,

Chief Paul Rich
Sheshatshiu Innu Band Council

cc: Peter Penashue, President, Innu Nation
Shirley Serafini, Deputy Minister, INAC

Sheshatshiu Innu Immediate & Long Term Needs
November 23, 2000

IMMEDIATE NEEDS

1. LEGISLATIVE AUTHORITY AND MANDATES

a) Child protection and family services (apprehension, placement, treatment follow up)

b) Peacemaking and policing authority

c) Education; band controlled school (k-high school)

2. CRISIS INTERVENTION

- full time crisis coordinator (for immediate situation and for beginning process of development of community crisis response team)
- capability to provide emergency relief staff as current community workers are reassigned

3. DETOX PROGRAM

- resources to provide secure, 24 hour detox facility (no access to solvents)
- training for staff in a secure detox

4. RECREATION PROGRAMS

- *staffing and resources for a recreation department*
- *Vehicle (van or small bus) for transportation of youth to recreational activities*

LONG-TERM NEEDS

1. DETOX PROGRAM

- community based, secure 6 bed facility (continuous intake)

2. FAMILY TREATMENT PROGRAMS

i) Treatment Facility (country based, year round access) e.g. Lobstick Lodge

- full time family treatment director
- program resources for blocks of treatment and staffing

3. COMMUNITY BASED RESOURCES & PROGRAMS FOR CHILDREN & FAMILIES

- Resource center for Innu Heritage and Living Culture
  - full time staff person and facility supports & mushimit coordinator
  - to promote and support country life and skills
  - to develop history and cultural awareness programs for Innu
  - to develop Innu language programs and resource materials
  - establish archives of materials
- establish office for full time coordinator and coordination of community social services
- modifications to the CJAY Restoration Center to have capacity for some secure beds for youth treatment
- establish community center with on-call worker resources
- capability to provide community based emergency child care placements
- resources for community inquiry (AHF proposal) into Innu experience with village transition
- resources to deal with issues coming out of inquiry (loss of self determination, sexual abuse, substance abuse *etc.*)
- develop ongoing programs within community to address issues of healing including the following: parenting programs, relationship work, AA, etc.
- front line staff support services - 'care for the caregiver'
- new school facility - Band Council controlled
- capacity to establish restorative justice program office and staffing
- capacity to provide staff training and development in relation to areas of need as well as staffing relief for community workers

July 13, 2000

Letters to the Editor
The Telegram
PO Box 5970, St John's NFLD
A1C 5X7

Dear Editor:

This coming September 9, 2000, Saturday, will be the second celebration of International FASDAY.

Your paper, to my knowledge, was the only media in Newfoundland and Labrador that acknowledge the first last September 9, 1999.

This letter is to remind all concerned individuals, organizations, municipal and provincial government agencies of the second FASDAY in advance and encourage them to plan appropriate activities in conjunction with many places in the world acknowledging the ongoing epidemic of Fetal Alcohol Syndrome (FAS)/ Alcohol Related Neurodevelopmental Disorder (ARND).

" During any given week in Canada, about 10,000 babies are born, about 20 of these babies are born with FAS and about 100 are born with ARND."

The comprehensive lifetime cost of just one baby with FAS/ARND could be as much as 6 million dollars. The cost to Canadian taxpayers for FAS/ARND is estimated to be 300 million each year.

In Newfoundland and Labrador , in 1998, it was estimated that there were about 5000 children, adolescents, and adults with FAS/ARND. The financial cost in dealing with their needs involving the medical, educational, social, and justice system is staggering excluding the non-quantifiable psycho-emotional cost to affected individuals, families, and caretakers.

I commend Premier Brian Tobin's recent statement on alcohol abuse but it should be made clear that alcohol abuse is not a geographic, ethnic, or social class problem. It affects all socioeconomic class in our province. It is, in most instances a complex medical, social and economic problem for 5-10 % of the general population and doing something for only part of the complex situation do not work. All its interrelated components need to be addressed concurrently.

Each of us has a responsibility in the prevention of FAS/ARND but we need responsible local and provincial government initiatives and effective programs to prevent the birth of more FAS/ARND individuals.

FAS/ARND is 100% preventable and 100% permanent!

We should all do what we can to encourage each other and government to actively prevent/minimize this ongoing epidemic. FAS/ARND is our problem and ours to solve. Everyday should be FAS/ARND prevention day. The possible FAS/ARND individual you save maybe somebody dear to you.

It was painful, each time I had said to parents that their child has FAS/ARND. And a tragedy to inform some families that in their case, 2 or 3 generations of FAS/ARND individuals were recognizable.

It is within all of us, our society, and our government to stop this epidemic. We do not know the amount of alcohol considered safe during pregnancy, thus abstinence is the best option. Alcohol and pregnancy should not mix.

Would/should an individual with FAS/ARND be able to sue his/her mother/parents, government and specific alcohol distilleries in the not too distant future for causing/contributing to his/her permanent disabilities?

Judging by what is now going on with the tobacco industry with multiple legal cases brought against them by individuals, interest groups, and governments the above question is very much a future likely development in one form or another.

I hope the above scenario would not become a reality as the best solution is not the financial compensation for these permanently brain injured individuals who had no say regarding their completely preventable state.

For those who would like to actively put into action their concern on Sept. 9, 2000 the Web page http://www.come-over.to/FASDAY/ is a comprehensive resource for ideas/activities to do.

Let us put Newfoundland and Labrador ~~in~~ ON the world map on FASDAY.

Yours sincerely

[redacted]

Ted O. Rosales MD FRCPC
Janeway Genetics Clinic
Tel # 778-4345

FAS and FAE:

A Report on Prevalence and Prevention Activities in Newfoundland and Labrador

Nicole Smith and Dr. T.O. Rosales

Nicole Smith
Tufts University School of Medicine
Department of Community Health
136 Harrison Avenue
Boston, MA 02111
NSmith1@opal.tufts.edu

Dr. T.O. Rosales
Medical Genetics Program
Janeway Child Health Centre
Janeway Place
St. John's, NF A1A 1R8
TRosales@morgan.ucs.mun.ca

This project was carried out in partial fulfillment of Master's degree in Public Health. Nicole Smith is currently enrolled in the combined MD/MPH program at Tufts University.

Dr. T.O. Rosales is a pediatrician/geneticist at the Janeway Child Health Centre and Associate Professor of Pediatrics in the Faculty of Medicine at Memorial University of Newfoundland, Canada. He sees many of the children diagnosed with Fetal Alcohol Syndrome or Effects in Newfoundland and Labrador and has an interest in increasing prevention activities across the province.

Table of Contents

INTRODUCTION

The Journal of the American Medical Association reported in 1991 that Fetal Alcohol Syndrome (FAS) is the leading known cause of mental retardation. This disorder, as well as the related Fetal Alcohol Effects (FAE) are caused by ingestion of alcohol while pregnant. The effects of FAS and FAE are permanent and, in most instances, irreversible, but both are entirely preventable simply by not drinking during pregnancy. FAS is the full blown physical manifestation of teratogenicity invariably associated with mental, developmental and behavioural problems. FAE is typically used to describe the mental, developmental and behavioural problems present when no or minimal physical abnormality is appreciated. Some recent publications suggest that FAE may not be a clinically useful diagnostic term as there is little uniformity in its application. New terms have been introduced, defined as "clinical conditions in which there is a history of alcohol exposure and where clinical or animal research has linked maternal alcohol ingestion to an observed outcome."[2] Alcohol- related neurodevelopmental disorder (ARND) refers to CNS and behavioural abnormalities, and alcohol- related birth defects (ARBD) to congenital anomalies. These terms are not yet in widespread usage, so for that reason as well as ease of language, this report continues to use "FAE." The symptoms of Fetal Alcohol Syndrome and Effects are most readily apparent in childhood. It is not uncommon for children to be subjected to batteries of tests, screenings and evaluations without ever discovering what is at the root of their problems. The problems continue to progress into adulthood at which time "maladaptive behaviors present the greatest challenge to management."[1] Over a life time, each case of FAS becomes an enormous drain on medical and educational resources.

The past fifteen years have seen a growing interest across North America in FAS/E. Several provinces have made great efforts to increase awareness and prevention programs on FAS/E, most notably British Columbia. FAS/E have been known in Newfoundland and Labrador for many years, but unlike in other provinces, no data has been collected on prevalence of the disorders. Recent interest in initiating prevention campaigns has been hampered by the lack of province-specific information, and just as importantly, the lack of established and ongoing communication between physicians, Community Health professionals, caregivers, and other interested parties.

In 1998, we embarked on a project with the dual goals of estimating the prevalence of FAS/E in Newfoundland and Labrador, and developing a better understanding of the state of FAS/E prevention and treatment activities in the province. We hope that gathering this information will not only increase awareness of the scope of the problem, but also help to foster communication between those parties interested in reducing the incidence of FAS/E and in helping those affected by the disorders.

This report is prepared in three parts. Some effort is first made to estimate the prevalence of FAS and FAE in the province. Statistics involving alcohol use during pregnancy are also discussed.

The second section is an overview of province-wide activities in primary, secondary, and tertiary prevention. Specific areas addressed are public awareness, prenatal education, identification of cases at birth, getting diagnoses, support for school age children with FAS/E, and availability of resources for caregivers.

The final segment consists of concluding remarks as to the efficacy and sufficiency of those programs in place, as well as some discussion of possibilities for the future.

PART 1: GETTING THE NUMBERS

The social stigma associated with alcohol consumption makes it very difficult to collect any accurate data on drinking, particularly drinking during pregnancy. However, to plan interventions and identify target populations, one would like to know how many women drink during their pregnancy, as well as how many children are born with Fetal Alcohol Syndrome or Effects. These numbers have never been compiled in Newfoundland and Labrador, and the reporting systems are not in place such that it would be possible to collect them. This study very roughly estimates those values by applying incidence and prevalence rates from other regions to population data from Newfoundland and Labrador.

Alcohol and Pregnancy

Various studies report rates of alcohol consumption during pregnancy. Many either have a small or homogeneous sample, making it inappropriate to generalize the results to other populations. The 1992 United States National Pregnancy and Health Survey is considered reliable. Among the results of interest here are calculations of alcohol use during pregnancy by age group and trimester. The data suggest that significantly more women drink during the first trimester than the second or third, and that women over 25 years of age are significantly more likely to drink during all trimesters than younger women. In this study, the lowest group rate of drinking during the first trimester was 10.6 percent in the under 25 group.(The highest was 19 percent in the over 30 group)[3] One may then assume that 10.6 percent is a fairly conservative estimate to apply to the entire Newfoundland and Labrador population.

Applying this data to Newfoundland and Labrador, the assumption was made that in 10.6 percent of all live births, the mother drinks during the first trimester. The average number of births per year in the period 1990 to 1995 was 6748.[4] An average of 715 women per year may have thus exposed their fetuses to alcohol during this most sensitive period of development. A great number of women stop or reduce alcohol consumption upon learning that they are pregnant; unfortunately this often does not occur until well into the first trimester. This fact only increases the number of women we may suspect of putting their children at risk for FAS/E. Although it is impossible to know how much any of these women drink, no amount of alcohol is proven to be safe during pregnancy. The children of these women must be considered at risk of FAS and FAE.

Prevalence of FAS and ARND

It is not clear how much drinking must occur before a child develops FAS/E. In addition, FAS/E are widely under- and mis-diagnosed, due both to difficulties in identifying the disorders and reluctance on the part of many physicians to "label." FAS and FAE are birth defects difficult to identify at birth. Diagnoses are by physical examination and extensive medical history rather than laboratory tests. These factors make it challenging to determine prevalence. Simply counting the number of diagnosed cases in this province is insufficient to determine the true number of affected individuals. However, enough studies have been done in other regions, as well as several meta-analyses, that a worldwide incidence rate of FAS has been estimated. It is more difficult to estimate incidence of FAE.

The most widely accepted worldwide incidence rate of FAS is 0.33 cases per 1000 live births. It is still favored by the Canadian Centre for Substance Abuse. The estimate is considered very conservative, and does not account for certain segments of the population that may be at higher risk due to socioeconomic or genetic factors. A more recent estimate by Ernest Abel, a well-respected researcher in the field, suggests that 0.97 per 1000 is a more accurate estimate of FAS incidence.[5] This rate may seem high, but is actually significantly lower than many others reported in the literature. Sampson, another prominent figure, suggests that rates may range from 1.3 to 4.8 per 1000, depending on the population.[6] Both Abel's and Sampson's rates are based on meta-analyses of heterogeneous populations, making them quite reliable.

Very few studies have attempted to estimate rates of FAE. This is partly due to a lack of uniformity in diagnostic criteria. Using a newer definition, however, Sampson suggests that the combined prevalence of FAS and ARND may be as high as 9.1 cases per 1000 people.

To estimate the prevalence of FAS/E in Newfoundland and Labrador, the above rates were applied to data from the 1991 Canadian Census.[7] Many programs are initiated on a regional basis, therefore calculations were made based on Community Health regions rather than census tracts. Regional population counts from the 1996 Census have not yet been released, therefore 1991 values were used. To allow two perspectives, estimates of FAS prevalence were first made by assuming a rate of 0.33 cases per 1000 people, and then repeated using Abel's rate of 0.97 per 1000. To estimate the combined total number of cases of ARND and FAS, Sampson's rate of 9.1 per 1000 was applied to the data. While ARND is not equivalent to FAE, this estimate is still valuable for the purposes of this paper.

Prevalence Results

Assuming a rate of 0.33 per 1000, the total number of expected FAS cases for Newfoundland and Labrador in 1991 is 187, with 54 in the St. John's area alone. With a rate of 0.97 per 1000, that total increases substantially to 551. The actual number of

diagnosed cases is less than 40 among all age groups, in the entire province. Even using the most conservative estimate, it is obvious that a great number of cases of FAS are being missed.

The combined total of ARND and FAS cases, using the rate of 9.1 per 1000, is estimated at 5173 province-wide. It is unknown how many diagnosed cases of FAE there actually are in Newfoundland and Labrador.

For all regional results, please see Figures 1 and 2.

PART 2: ACTIVITIES ACROSS NEWFOUNDLAND AND LABRADOR

Prevention activities range from population-based education campaigns to special education in schools. While some programs may seem to have little in common, they all have the potential to decrease the burden of FAS/E in the province.

Most information here was collected through conversations with individuals involved in health-related programs and organizations across the province. Therefore some information may be coloured by the opinions of those involved. Others working in the same areas may have differing views as to the efficacy of those programs.

Primary Prevention: Averting the Problem

Minimal primary prevention of FAS/E is being done in Newfoundland. The pamphlet "Alcohol and Pregnancy" is distributed during Drug Awareness Weeks at schools. Public Health nurses at schools sometimes discuss the dangers of drinking when pregnant. The Care Center for Women in St. John's attempted to hold an FAS and folic acid education evening, but disappointingly little interest was shown by the community in the event. Planned Parenthood does not do prevention work against FAS/E at this time.

In Labrador, prevention programs are being established by both Community Health and the Labrador Inuit Health Commission (LIHC). The LIHC sponsors posters, radio spots and school programs on how to have a healthy baby, which include discussion of alcohol. Community Health Labrador, in conjunction with provincial representatives, is currently initiating a one day workshop on FAS that will target everyone from health care professionals and teachers to parents.

Community Health Addictions Services across the province all express some interest in Fetal Alcohol Syndrome and Effects, and provincially are considering becoming more active in FAS/E prevention. Discussion is beginning on the provincial level for a FAS/E awareness campaign. In October 1996, an interdisciplinary FAS/E Workshop was held to create a provincial action plan and FAS/E Committee. These goals were never realized.

The Newfoundland Liquor Corporation is presently investigating possible programs to promote safe use of alcohol. They are in the early planning stages and do not know what form these programs will take.

Secondary Prevention: Targeting those at Risk

All pregnant women can be considered at risk for FAS/E. Therefore any occasion on which a woman receives health information is an opportunity to pass on a message of prevention. Most often that is when women get prenatal care.

Prenatal Education

There has been some effort in various programs to educate women of the risks associated with drinking alcohol during pregnancy. Little communication takes place between organizations, leading to the perception among some that more education is taking place than is the case.

Among those groups providing prenatal education are physicians, prenatal education classes, public health nurses, Healthy Baby Clubs, reproductive health clinics such as the Care Center for Women, and schools. These parties are actually providing education to varying degrees.

Physicians have the greatest opportunity to educate women as to the dangers of drinking during pregnancy, and to identify women that may be having difficulties that could lead to alcohol abuse. The prenatal record should encourage discussion of alcohol use and referrals when alcohol abuse is suspected. Addictions Services has not received any referrals to date through this route. Several explanations have been put forth to explain this. Some suspect it is simply due to patients underreporting drinking, while others suggest that physicians are not comfortable inquiring about alcohol use. Anecdotal evidence suggests that some physicians do not investigate at all their patients' use of alcohol. The term "Addictions" dissuades some physicians from referring patients. This suggests that discussion should take place regarding what level of alcohol dependency is grounds for a referral. Significantly, no one knows just how much alcohol and at what times will harm the fetus. Some physicians inform their patients that regular use of alcohol in moderation is safe. There is no hard evidence to this effect. Physicians are not passing on uniform information to patients. The Canadian Paediatric Society joint statement reads "Health Professionals…must provide consistent information to women and their partners that the prudent choice is not to drink alcohol during pregnancy."[8]

Prenatal education classes differ by region. FAS/E is not a priority in the St. John's area, and these classes may not be sufficiently addressing alcohol use during pregnancy. In other regions, prenatal education topics may vary by group instructor, therefore generalizations regarding educational content are difficult to make. Prenatal education classes may be inherently limited in their capacity to prevent FAS/E, simply because women may enroll

(at least in the St. John's region) up to their twentieth week of pregnancy. This may well be too late to protect the fetus.

Public heath nurses have the opportunity to do a great deal of education. Again, the degree to which individual nurses discusses alcohol effects differs by region and whether other medical and public health resources are available in that area.

Healthy Baby Clubs have an excellent chance to effect a change in habit simply due to their intensity. Women spend an average of 25 group hours and 16 individual hours in the program; this promotes the development of trusting relationships and provides many opportunities for education. Unfortunately, Healthy Baby Clubs are also very expensive. Provincially only about 450 women participated in the last two years. Therefore while they may have a great impact on participants, they are not widespread enough to make a difference at the population level. In a recent evaluation, only eight percent of participants reported drinking during pregnancy.[9] How data was collected was not reported. Comparing these results to those from the U.S. Pregnancy and Health study suggests that this is an underestimate. That supposition is supported by the facts that women are highly likely to underreport alcohol consumption, and that many women do not know they are pregnant until well into their first trimester. In this way many women may unknowingly expose their children to alcohol. Alcohol use is discussed in the Clubs, but again, is not a priority.

Tertiary Prevention: Preventing Recurrence and Lessening Effects

Tertiary prevention occurs once the damage is done. The focus is on the child and the family.

Birth

The *live birth registration form* carries a check box for FAS. It is very seldom used and data on its use are not collected. In addition, the perinatal clinic has very rarely seen infants identified with FAS at birth.

Identifying a child with FAS/E early in life can have a significant impact on his/her outcome. If the child spends the first years of life in stable, stimulating, loving and supportive surroundings, his/her prospects are much brighter. When no intervention takes place until school age, it is infinitely more difficult to alleviate many developmental and behavioural problems.

Getting a Diagnosis

FAS in particular and FAE in general are notoriously difficult to diagnose. In addition, some health professionals question the importance of "labeling" when the disorders are irreversible and a diagnosis may confer a social stigma. Labeling is the primary argument against diagnosing. There are several significant arguments in favor of diagnosis. Most

importantly, getting a diagnosis assists caregivers, teachers and the affected child most effectively deal with the associated mental, developmental and behavioural challenges. A diagnosis may help explain why a child seems to have difficulty listening to or following instructions. This said, diagnosis is often a non- issue as the majority of physicians are not sufficiently comfortable with the symptoms and physical manifestations of FAS/E to make a diagnosis. Interestingly, the problem also goes in the other direction. Abel reports that in a few regions physicians are too quick to see FAS/E in every behavioural difficulty or learning disability.[10]

With this background, it is not surprising that very few diagnoses of Fetal Alcohol Syndrome or Effects are made. The vast majority of these are made by the Medical Genetics Clinic at the Janeway Child Health Centre. There are other circumstances in which a diagnosis may be made or suspected. These are in Youth Corrections, where it is estimated that two to three teens per year with obvious but undiagnosed FAS or FAE are seen, and in the schools, where teachers or other staff may suspect FAS/E but not suggest a medical referral. The most significant problem in these situations is that other conditions may mimic FAS/E. A physician experienced with FAS/E should be consulted to establish a diagnosis. For the most part such physicians are found only in the St. John's.

There is a growing feeling in some regions that more diagnoses should be made. In some parts of Labrador, many children are currently being diagnosed with Attention Deficit Disorder (ADD). There is some speculation that in a subset of these cases FAS or FAE may be the true diagnosis.

It bears repeating that there are currently fewer than 40 diagnosed cases of FAS in the entire province. If one assumes the estimate of 0.33 cases per 1000 people to be accurate, there should be at least 50 cases in the St. John's area alone. There is no question that 40 enormously underestimates the problem.

School Age

School presents a challenge for many FAS/E affected children. If their particular needs are not addressed they may simply be dismissed as stubborn or disinterested in school work. While most diagnosed children with Fetal Alcohol Syndrome or Effects are receiving some extra help in school if those services are available, new changes in special education policy should help them further. Beginning September 1998, FAS/E are qualifications for Categorical Special Education. Giving a diagnosis of FAS/E may therefore help children and their families access additional help in school. The Individual Student Service Plan (ISSP), which assembles an interdisciplinary team for each student who needs assistance, should also help to ensure that children get the help they need. The fact that some parents will be intimidated by a room full of professionals should not be overlooked.

Other professionals may provide some aid outside of school. Behaviour management specialists may be consulted, but unfortunately these professionals are not always familiar with the specific needs of FAS/E affected children, for whom traditional behaviour

modification is commonly not the most effective approach. Social workers are often involved as many children with FAS/E are in foster care. However, social workers often have too heavy a caseload and are reassigned too frequently for them to develop a relationship with these children. Child management specialists have been an excellent resource for caregivers in some regions.

Medically, child development and/or mental health professionals may see some children. This depends on the severity of the child's problems and how well they and the family are coping.

Unfortunately, limited funds make it impossible for any organization to provide as much care as they would like. Even children with well-understood learning difficulties may not receive the help they need due to shortages in staff and, as one school board official put it, the "overwhelming bureaucracy" involved in accessing special help. In many parts of the province, school resources are inadequate to meet the needs of the community.

Educational Resources

Educational resources available for parents of children with FAS/E are currently extremely limited. The Arts and Culture Center Library holds only three titles relevant to parents, two of which are videos. The Addictions Services Library has a much broader selection, but is not advertised to the public. Although this latter library is technically open to the community, in practice it is only used by professionals and students. There is a great deal of information available on the World Wide Web, but a combination of most people's limited access to the Internet and the information being difficult to locate makes this source of questionable value on a community level.

Part 3: Conclusions

Fetal Alcohol Syndrome is a serious, pervasive problem in many communities. It is too often misdiagnosed or simply overlooked. As a result, many families are not receiving the assistance and support that would help them successfully parent their child, while children are not getting all the help they could to succeed in school and in life.

There are currently less than 40 diagnosed cases of FAS in the province. Using the accepted worldwide rate of 0.33 cases per 1000 live births, the expected number of cases across the population is 187. With the more recent suggested rate of 0.97 per 1000, the number of expected cases rises to 551. No good estimates of FAE incidence or prevalence are available, though the combined prevalence rate of FAS and ARND has been suggested to be 9.1 per 1000 people. That rate gives an expected 5173 cases across the province.

In Newfoundland there is an overall fair to poor awareness among professionals regarding the disorders Fetal Alcohol Syndrome and Fetal Alcohol Effects. The lay public is, in general, not sufficiently informed of the danger of alcohol use during pregnancy: a problem compounded by the unavailability of resource material. Neither group has an

understanding of the enormity of the problem. In Labrador, there is a greater cognizance of the prevalence and significance of FAS/E, but also a feeling that for change to be achieved, other socioeconomic factors must be simultaneously addressed. By improving prevention activities across the province, women will be given a better opportunity to make healthy choices for their children. A province-wide campaign should integrate messages of prevention from health care practitioners and public health officials. Incorporating a message of the dangers of alcohol in pregnancy into a community-based intervention has been the most successful approach in other regions of the country. For real change to occur, increased public awareness must begin at the school level.

Groups involved in providing prenatal education have an excellent opportunity to stress a message of prevention. Capitalizing on that opportunity is the least expensive way to increase awareness of FAS/E. The Canadian Centre on Substance Abuse states in their policy discussion paper that "If [pregnant women] want to avoid all risks of fetal alcohol effects, less drinking is better and none is best."[11] The Government follows that "no safe level of alcohol exposure has been identified for the unborn baby."[12] Every health care practitioner can disseminate these messages.

Raising a child with Fetal Alcohol Syndrome can be an exhausting and often very frustrating experience. These difficulties can be exacerbated if professionals are inadequately educated in the needs and challenges of children affected with FAS/E. Teachers and specialists may help a child, but as resources are extremely limited, it is the family that makes the most significant impact in deciding that child's fate. FAS/E in one child can be indicative of alcohol effects in siblings or difficulties in the home. Caregivers are struggling to deal with these issues while often simultaneously trying to create a safe and supportive home. They are receiving virtually no assistance in terms of advice or support. More information should be made available to caregivers so that they may better help the children.

The only way to solve the problems of Fetal Alcohol Syndrome and Effects is to educate and support parents before they become pregnant. That education must be a unified effort among community health professionals, physicians, community leaders and government agencies. Current efforts to prevent and alleviate FAS/E in the province are mired in the lack of communication among interested parties. Disparate groups should work together to spread a message of prevention. Limited resources available to individual organizations make a concerted effort among groups the most economically realistic approach. However, until those social and economic factors that lead people to drink are addressed, it is unlikely that FAS or FAE will ever be fully prevented. For this reason, effort should be also be made to educate parents, teachers, physicians and other support professionals in how to best aid FAS/E affected children and their families. In this way, affected children will be better able to achieve their full potential, and the cycle of further abuse will be prevented.

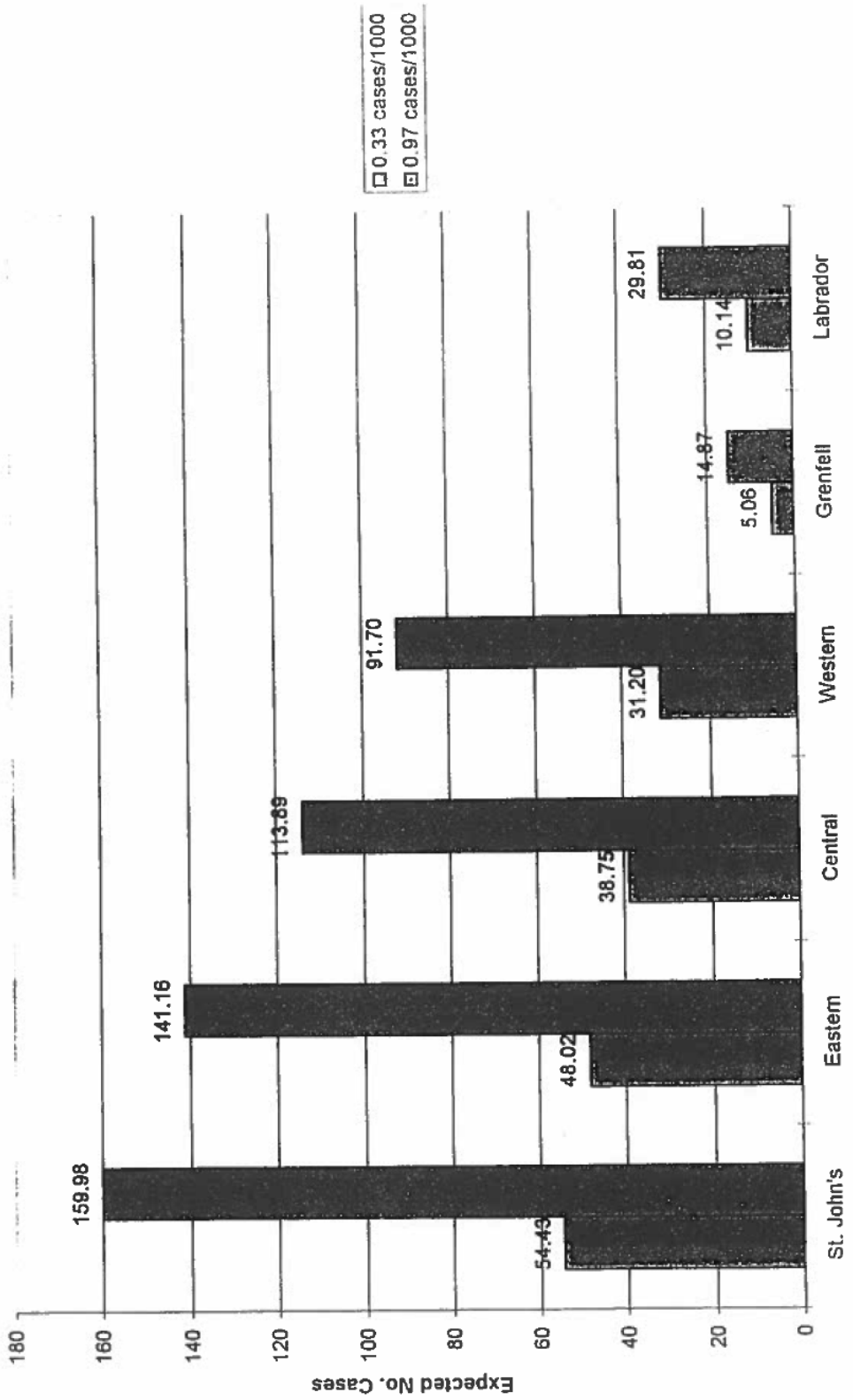

Figure 1: Comparing Expected FAS Prevalence By Two Rates

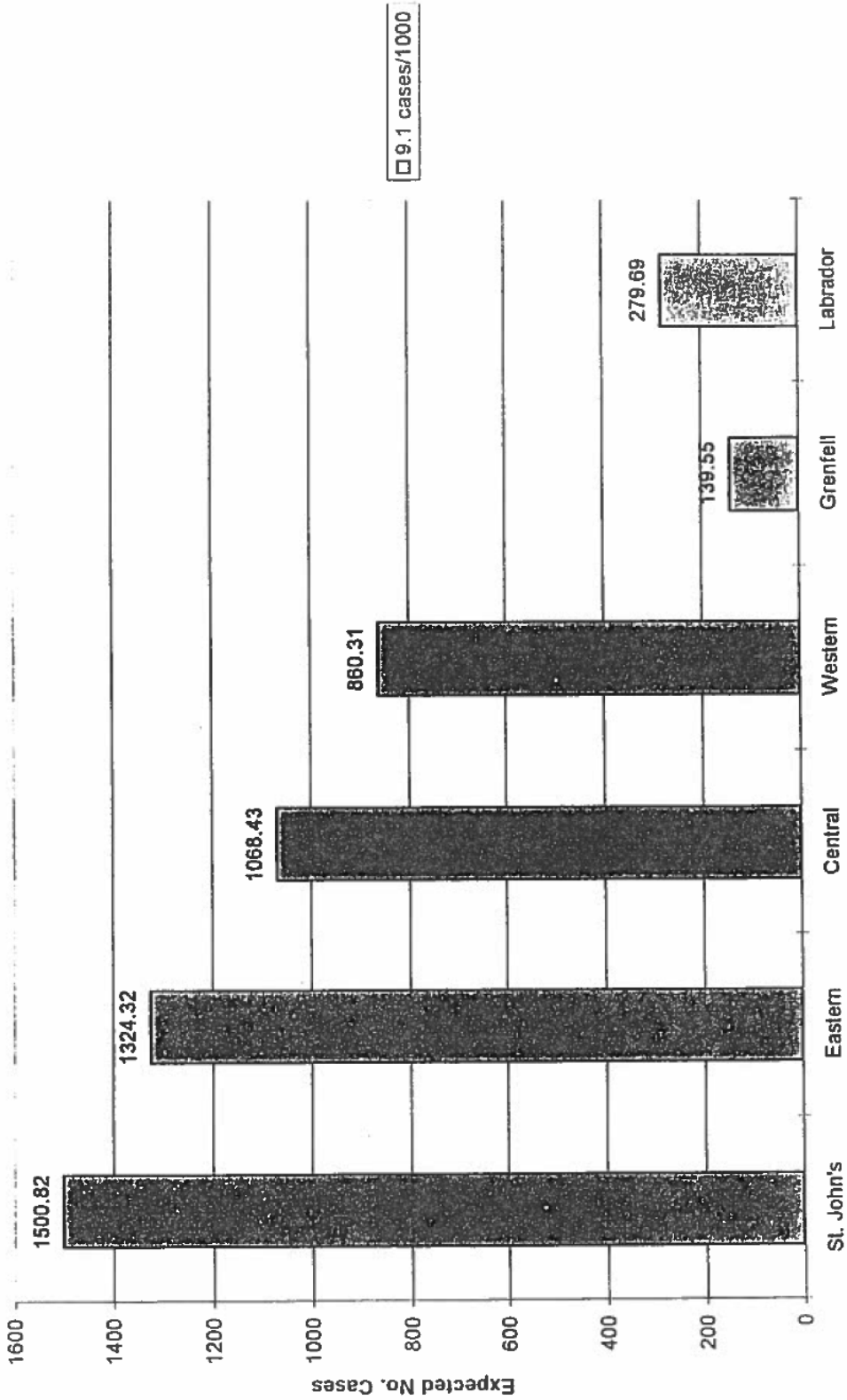

Figure 2: Expected Prevalence of FAS + ARND by Region