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**Official Report
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(Hansard)**

Wednesday 19 May 2004

**Journal
des débats
(Hansard)**

Mercredi 19 mai 2004

**Standing committee on
regulations and private bills**

Sandy's Law
(Liquor Licence
Amendment), 2004

**Comité permanent des
règlements et des projets
de loi d'intérêt privé**

Loi Sandy de 2004
(modification de la loi
sur les permis d'alcool)

Chair: Tony C. Wong
Clerk: Trevor Day

Président : Tony C. Wong
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LEGISLATIVE ASSEMBLY OF ONTARIO

ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

**STANDING COMMITTEE
ON REGULATIONS
AND PRIVATE BILLS**

**COMITÉ PERMANENT DES
RÈGLEMENTS ET DES PROJETS DE LOI
D'INTÉRÊT PRIVÉ**

Wednesday 19 May 2004

Mercredi 19 mai 2004

The committee met at 1002 in committee room 1.

**SANDY'S LAW
(LIQUOR LICENCE AMENDMENT), 2004**

**LOI SANDY DE 2004
(MODIFICATION DE LA LOI
SUR LES PERMIS D'ALCOOL)**

Consideration of Bill 43, An Act to amend the Liquor Licence Act by requiring signage cautioning pregnant women that the consumption of alcohol while pregnant is the cause of Fetal Alcohol Syndrome / Projet de loi 43, Loi modifiant la Loi sur les permis d'alcool en exigeant que soient placées des affiches avertissant les femmes enceintes que la consommation d'alcool pendant la grossesse cause le syndrome d'alcoolisme fœtal.

The Chair (Mr Tony C. Wong): Good morning, ladies and gentlemen. This is the standing committee on regulations and private bills. I want to welcome members of the public to this meeting. We are dealing with Bill 43, An Act to amend the Liquor License Act by requiring signage cautioning pregnant women that the consumption of alcohol while pregnant is the cause of Fetal Alcohol Syndrome.

We have a number of groups who have requested to speak to us. I just want to impress upon you that we are operating on a very tight time schedule, so each group has been given eight minutes. If there are questions from members of the committee, those would have to be dealt with within the eight minutes. So we'll appreciate it if you can limit your comments to maybe six or seven minutes.

**FETAL ALCOHOL SYNDROME
TREATMENT AND EDUCATION CENTRE**

The Chair: I'd like to invite the first group, the Fetal Alcohol Syndrome Treatment and Education Centre, Jill Dockrill and Janice Alexander, to come forward, please. We already have your package. Welcome. You can start now.

Ms Jill Dockrill: Good morning. My name is Jill Dockrill and I am the director of the Fetal Alcohol Syndrome Treatment and Education Centre in Belleville. Beside me is Janice Alexander, our program developer. We are the only non-profit organization between Ottawa

and the Durham region devoted solely to FASD issues. I appreciate the opportunity to speak to you today in support of Sandy's Law and I commend our local MPP, Ernie Parsons, for the strength, courage and vision that has allowed him to bring forward this bill.

Raising awareness about the dangers of alcohol during pregnancy is vital. Sandy's Law is an important step toward the day when no more babies are born with fetal alcohol spectrum disorder. With signs that are large enough, clear enough and specific enough, Sandy's Law can help correct some of the many misconceptions about alcohol and pregnancy. It will help spread the word that when a woman is pregnant, there is no safe time, no safe amount and no safe kind of alcohol. FASTEC believes Sandy's Law is a great first step for Ontario. Unfortunately, no matter how effective these new signs are, more babies will be born, today and tomorrow, damaged by alcohol. New signs will not change the lives of those now living with FASD.

Children born in Ontario with FASD often face a grim future. Pre-natal alcohol use can cause irreversible brain damage. Bones, limbs and fingers may form improperly. Alcohol causes vision and hearing difficulties and can damage the heart, kidney and other vital organs. Many of these children will require lifelong assistance with daily living. They exhibit memory and attention deficits and hyperactivity. They can display immature behaviour, have poor judgement and impulse control, and problem-solving skills are limited. Often these children end up in foster care and group homes. Branded as troublemakers at school and without effective support structures, they begin a journey of conflict, suspensions and frustrations that too often result in contact with the law. As adults, they are at high risk for drug abuse, alcoholism and an early death. They swell the ranks of our homeless, unemployed and prison populations.

At FASTEC, we know that with early diagnosis, along with supports and services designed specifically for FASD, those affected can reach their potential. Our goal is to open a six-bed, specialized, supportive home for those with FASD. One bed would be held for respite. We currently have a waiting list of four people.

Sadly, in Ontario today much of the supportive housing we provide for the adult FASD population is a prison cell. This is a very expensive choice. Corrections Canada estimates that 42% of inmates in our prison

system have some form of FASD. Research also indicates a disproportionate number of alcohol-affected young people in the youth justice system.

It is important to understand that because of brain damage, people with FASD do not learn from the consequences of their actions. They may be unresponsive to traditional interventions. This disability is a shared responsibility of human service agencies. It takes a community working together to foster improved outcomes for children and adults with FASD.

In the handouts you have received today, I have included *A Child's Plea*, *A Mother's Story*, which tells of the life of my adopted son, Tom, who has fetal alcohol effects. I hope you will take the time to read it. This story typifies what families in Ontario go through to get help. In 2001, my son, Tom, and his dog, Shadow, walked across Ontario to raise money for FASD. This was the beginning of FASTEC.

FASTEC has now been operating on a shoestring budget for three years. Every penny we have comes from donations. With our hard-earned funds we run a support group for FASD individuals and their families. We raise awareness about the dangers of prenatal alcohol consumption, and this year we are finally able to open an FASD resource centre.

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We are now starting the next phase of our work by developing formal training programs for health care professionals, service providers, teachers, law enforcement and justice agencies, but we cannot do this alone. We need your help.

This government cannot afford to start from square one to bridge the gaps that exist in services. We have too much work to do. We must build on what has already been accomplished elsewhere. A good example of where to look is as close as Canada's three western provinces. I recently completed a comprehensive training program in British Columbia, where I learned of routine early diagnosis, specialized supports and services, and alternative sentencing programs that we have only dreamed of.

Ontario has the capacity, talents and resources to become a world leader, setting new standards for how society treats those harmed by prenatal alcohol consumption. What we need from our government is the determination, the investment and the leadership. I know you will not let us down.

The Chair: Thank you very much. You were almost perfect in your timing. You have spent seven and a half minutes. Questions from members of committee? If not, thank you for making the interpretation for us.

CENTRE FOR ADDICTION AND MENTAL HEALTH

The Chair: I call on the second group, the Centre for Addiction and Mental Health, to come forward: Dr Peter Selby. Welcome, Dr Selby. Just to remind you again, eight minutes, please.

Dr Peter Selby: Sure. I want to thank everybody for giving us this opportunity. I represent the Centre for Addiction and Mental Health in Toronto. For those of you who don't know, we're the largest mental health and addiction facility in Canada. Our mandate is as a hospital locally but also provincially, and we have some work that we do internationally and nationally as well.

We support any effort to make sure the public has the information to make informed choices about the use of alcohol. We certainly support this legislation, as signage will provide another avenue to get the public the information needed to make an informed choice about the use of alcohol.

I'm not going to go over the whole issue of FAS, because I think the other groups have done that for you, but I'd like to speak much more to how this act can fit into a larger, more comprehensive plan that is necessary if we are truly committed to reducing the exposure of neonates or fetuses to alcohol. This is just one part of a comprehensive strategy. This legislation should be accompanied by a continued commitment to healthy public policy, ongoing public education, and an effective and available treatment system.

One of the biggest tenets in medicine is that you don't go looking for conditions for which you don't have treatments, because that's ethically unfair. So if we are going to be raising awareness or we are going to tell women about their drinking and there aren't venues for them to go get the treatment and the help that they need across the breadth and expanse of this province, we've really got to ask ourselves what we're doing to people. So clearly this needs to be part of that larger, comprehensive policy.

We also know that knowledge rarely results in behavioural change; however, it's a very important first step to making movement in behaviour. So the signage should be enacted in order to reinforce, but not replace, other forms of education.

The greatest value in this approach is that exposure to alcohol and signage are linked. It is where alcohol is consumed that people will get to see this. We think that's a very important way of getting the message to the people who most need to get the message. Even if its overall effectiveness is very low, because it's relatively inexpensive and it will reach, relatively, a lot of people, it may have a huge impact.

Bill 43 deals exclusively with signage and cautioning pregnant women about the consumption of alcohol while pregnant. However, consideration should be given to expanding this because, as we know, about 50% of pregnancies are unplanned and many women don't know that they are pregnant. They may have already consumed alcohol in that critical first period, leading to a lot of effects of anxiety and fear. So to really be effective, attention should be paid to broadening this. Targeting this message and information to women of childbearing age and to the whole population needs to be given some consideration. We do know a woman's partner's drinking also directly affects her drinking. We need to think about

this. This is a good first step, but we need to think more broadly about this.

Again, as we know, alcohol-related birth defects are an important but small part of the harm that alcohol can cause to Canadians and Ontarians. We need to pay attention to the liver injuries and the other things that go on with alcohol consumption. General public education may also have a beneficial effect by reducing consumption overall.

Clearly, the industry that manufactures this has had a huge role to play in the reduction of drinking and driving, and certainly this is another area they could pay attention to.

The last major point that I would like to address to the committee is about the messaging and the implementation of signage requirements. It certainly requires an evaluation to see how effective it has been, what kind of impact it has had.

What we recommend is to take a look at evidence from the tobacco field where signage on cigarettes has had a huge impact in terms of the messages being noticed. There are some ongoing studies comparing signage in Canada versus the USA versus countries where there's no signage and what impact that has had on people in terms of the knowledge and awareness of the risks. Certainly something should be learned there.

Therefore, there should be regulations on the size, placement, font and colour combinations used to ensure that labels are seen and read. The language should be simple, clear and should not lead to easily labelling or stigmatizing people. Again, messages most likely to be recalled contain new information and should be convincing if they are personalized and relevant to the consumer. Therefore, if you can have some rotating messages that people have an option to use rather than a single message, that should certainly be considered. The messages should be properly tested before they're implemented. Evaluation should address the type and number of messages, specific wording—if the attribution to a health authority increases its credibility, then that should be considered as well—and the impact of the font, colour, placement and its use in English and French.

With respect to pregnancy, messages that are more specific, more positive and less well-known should be considered, such as, "Reducing alcohol use early in pregnancy greatly increases the chance of having a healthy baby"; "Women who drink during pregnancy should talk to their doctor"; "Drinking less alcohol during pregnancy is better, and none is best."

With that, I'd like to conclude my submission. Thank you very much for the time that you've given us.

The Chair: Thank you, Dr Selby. Any questions from the members of the committee.

Mr Ernie Parsons (Prince Edward-Hastings): Just very quickly, your comments about the sign are very well taken. There will be an amendment that will move it from the bill to regulations in the belief that there may be different size and colour signs appropriate for different settings and a concern that a sign can get stale after a

number of years, and regulations would provide the opportunity to change that, in consultation with other groups. Excellent suggestion.

Dr Selby: Thank you very much.

Mr Rosario Marchese (Trinity-Spadina): I wanted to thank you for your presentation and thank the previous group as well. I did have some comments or questions for them, but I'm sorry I didn't ask them.

The previous group and yourselves have talked about the idea of signage being a good first step. It's really hard to disagree with any of that, and the best thing is how to make it more effective, which is what you're all suggesting. The point they made is you need support services, alternative sentencing programs, which I think is critical, and early diagnosis. You talked about effective, available treatment.

In your view, do we have, at the moment, effective, available treatment? If not, what are we lacking, and what is your suggestion for the government, in particular and in general to all politicians, in terms of what we need?

Dr Selby: I want to talk about there being two people who maybe need treatment here. One is the pregnant woman who is consuming alcohol during pregnancy. You can look at the one who is uninformed but happens to have consumed alcohol, doesn't have a problem with alcohol per se, and because of a mistaken belief system continues to drink during pregnancy; not necessarily heavily, but continues to drink. That's by far the more common population, which is very amenable to public education. They are very amenable to things like taxation, messaging etc. So they don't necessarily need intensive treatment.

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The small group who do need to have treatment are the heavy drinkers who are addicted to alcohol. The treatment systems are getting there, but they're not there yet. We don't have very many women-specific treatment programs. Especially, there isn't coordination across the system in the province. Yes, we may have resources in Toronto, but I'm thinking of other areas, like Dryden or other places, that are remote. What kind of capacity do we have to help those communities deal with it?

There are two aspects of treatment. One is the pregnant woman, which is what I'm focusing on. Then the other one is a child who has been affected by FAS right from getting an early diagnosis. Most physicians are not very well—first, they don't know how to screen for alcohol in pregnancy; second, when a child is affected they are unable to recognize a child who's affected. So we don't have that capacity in sort of an international standing, given the kind of brainpower we have in Ontario, to actually respond to that.

Clearly policies that help for that capacity to develop are much needed to help these kinds of things to be effective.

I hope that answers the question.

Mr Marchese: Within the limited time we've got, yes.

The Chair: Thank you, Dr Selby.

FASWORLD CANADA

The Chair: I'd like to call on the third group, FASworld Canada, to come forward: Bonnie Buxton and Colette Philcox. Welcome. We have a copy of your submission.

Ms Bonnie Buxton: I'd really like to thank all of you for allowing me to speak about a preventable health disorder that is costing this province many billions of dollars annually.

Our family is extremely grateful to Ernie Parsons for proposing Sandy's Law. Like the other presenters, I believe it to be an important first step in preventing the brain damage that currently affects about one in 100 citizens of this province—over 100,000 people, most of them undiagnosed.

I'm also grateful to my daughter, Colette Philcox, for coming with me today. Unlike the beloved Sandy, she has a normal IQ. However, she too has struggled with the effects of prenatal alcohol damage.

When Colette was 17 years old, sliding on to the street, addicted to crack, I saw an item on CBC-TV and instantly recognized what our family had been dealing with for many years: neurological damage caused by prenatal alcohol.

We now know that her birth mother binge-drank through all three of her pregnancies and was most likely affected by prenatal alcohol herself.

I've documented our family's difficult journey in my recent book, *Damaged Angels*. I will be submitting one copy, along with copies of a newspaper article in the *Vancouver Sun*. The book took three years to research and write, and I interviewed parents, professionals and survivors all over the world. Some of them are in this room and will be presenting as well today.

As a result of my national and international research and advocacy, I'm making three requests. One, rather than referring specifically to fetal alcohol syndrome in the legislation, please use the more recent umbrella term "fetal alcohol spectrum disorder," FASD, which encompasses all fetal alcohol disorders, including FAS.

In brief, the term fetal alcohol syndrome now generally refers to individuals with full-blown FAS. These make up about 20% of the people with FASD. They generally have small size, small head circumference—many other physical characteristics—and fairly low IQs. But about 80% of individuals with FASD appear to be normal, but their learning and behaviour problems are invisible. Colette has been diagnosed with alcohol-related neurodevelopmental disorder, ARND, which was formally known as fetal alcohol effects, FAE.

Individuals with ARND generally have normal intelligence, but their learning problems usually include things like poor memory, difficulty in predicting consequences or learning from experience, poor judgment or lack of impulse control, and many quickly become addicted to alcohol and drugs. These people at the high end of the fetal alcohol spectrum, people like Colette, are at even more risk than individuals with full FAS, as they are

rarely diagnosed. The majority will drop out of school, will encounter trouble with the law and have great difficulty obtaining regular employment. By 21, many have brought two or more damaged babies into the world.

My second request would be similar to that of Dr Selby. I ask that the wording on the posters not be spelled out in the legislation but that it be flexible. There could be several messages developed in concert with people like the chief medical officer in consultation with various groups around the province. My research indicates that that kind of freshness and variety could give much more impact to the message, as it now does on the cigarette package warnings.

Finally, like everyone else here, I urge that the warning posters become this government's first step in fighting this terrible disorder which is costing Ontario taxpayers billions of dollars annually for social services, special education, mental health and addiction problems and criminal justice.

I estimate that, at 24, Colette's problems have so far cost the taxpayers more than \$1 million. These costs include foster care through CAS for the first three and a half years of her life—this would include the cost to the foster family and also the cost of administering foster care programs; psycho-educational testing at school and special education from fourth grade on; a residential treatment farm for so-called emotionally disturbed adolescents for two years; and a brush with the law at age 14, requiring legal aid and many hours in court.

She finally completed her high school diploma last year at age 23, for which we were very grateful and proud, through an excellent special education program offered by the Toronto District School Board.

She has had treatment for many health problems caused by prenatal alcohol exposure, such as frequent earaches, requiring surgery as a young child, dental problems, a heart murmur, and the back pain of scoliosis.

She currently lives on Ontario disability support, but could possibly work full-time—she's really gifted with animals—if she could find an employer who understands her disabilities. I estimate that the costs of administering ODSP, plus income support, drug and dental benefits probably are close to \$25,000 per year.

Colette has two young children, aged 3 and 4 and a half. She was committed to not drinking in pregnancy—unusual in women with FASD—but the children have required subsidized day care since infancy, costing the taxpayers more than \$20,000 per year. So between the ODSP and the daycare, that's \$45,000 per year for this little family. Fortunately, she has taken steps to prevent further pregnancies, and this is also very unusual for a young woman with FASD. Many will have four and five children before they're 25 years old.

The good news is that when diagnosed early and given adequate support, individuals with FASD can break the expensive and tragic cycle of alcoholism, poverty and abandonment. However, breaking the cycle requires a whole new way of thinking on the part of government. All of us presenting today would be pleased to work with

you in developing policy changes that can save money while tackling this terrible disorder. I'm giving Colette the last word.

Ms Colette Philcox: Please pass Sandy's Law.

The Chair: Thank you, Bonnie and Colette. Questions?

Mr Marchese: Just a quick one: Part of the problem that we have in Ontario with people generally attacking welfare recipients and ODSP recipients is that young people tend to look healthy.

Ms Buxton: That's right.

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Mr Marchese: You look at them physically and you say, "They're bums. They just don't want to work."

Ms Buxton: But you don't recognize that they've got disabilities inside.

Mr Marchese: Quite right. This is why sometimes I get very upset at certain politicians for the attacks they make and how they feed that anger against people who actually need help. How do we deal with that problem?

Ms Buxton: I think we somehow have to get the message that there are a lot of people out there with invisible disabilities. We see this in the media almost every day, where people have committed horrendous crimes, and then we look at them and we see that they are part of a dysfunctional family. They are foster children who grew up inside the foster care system. The Alberta statistics indicate that probably as many as 50% of foster children are actually struggling with FASD and 70% of those who become crown wards and available for adoption have FASD.

It's a message that we've been working very hard to get out. These people are as disabled as if they had feet and legs that did not work. It's been very hard to watch our daughter struggle as hard as she has, because she works very hard and yet she needs employers who really understand her. You can see she's bright and she's wonderful, and we love her to bits. She deserves better than she's had. I think every single parent who's here today feels that way about their children. We all just love them, and the supports have not been there for us as parents.

Ms Philcox: I hate to say that the government, the school system and the doctors have really let this disability down. Try and make a change, please.

Mr Marchese: Do we have time?

The Chair: A very short one.

Mr Marchese: How do you think the school system failed these types of individuals?

Ms Philcox: For me personally, I was told I was lazy, stupid, incompetent, that I could do better, when I was working my fullest. Being treated like I was an inch instead of who I am. Doctors basically saying, "Oh, you know, all these problems are just normal problems. They're not part of fetal alcohol."

Mr Marchese: Because the doctors couldn't identify the problem.

Ms Philcox: They didn't know anything about it. There's more research that has come out, but my family doctor knew nothing about it at all.

Ms Buxton: We spent seven years going through a trail of psychiatrists, psychologists and social workers, which I write about in my book. Only later did we encounter hundreds, maybe thousands, of other families across the country who were going through the same stuff.

Ms Philcox: The same story.

Ms Buxton: Even nationally and internationally. It's a huge, invisible issue and we are so pleased that the Ontario government is finally taking an interest in this, thanks to Ernie.

Mr Marchese: As a first step.

Ms Buxton: Yes, absolutely.

The Chair: Thank you both. Colette, on behalf of the committee, I want to commend you for your persistence and willpower to struggle on. Of course, you are fortunate to have Bonnie step forward and assist you.

Ms Philcox: Thank you very much.

FASWORLD HAMILTON

The Chair: I want to call on the next group, FASworld Hamilton, May Stanley and John Stanley. Welcome both and, yes, we have your submission.

Ms May Stanley: Good morning, Mr Chairman and committee members. My name is May Stanley. I'm from Oakville. I'm proud to be accompanied here today by my son, John. We both thank you for this opportunity to express our support for Bill 43, Sandy's Law.

Fetal alcohol syndrome disorder is permanent brain damage. If this law is passed, you as a government will be in good company. This quote is from Aristotle: "Foolish, drunken or hare-brained women most often bring forth children like unto themselves." and from the Bible, Judges, chapter 13, verse 7: "Behold, thou shalt conceive, and bear a son; and now, drink no wine nor strong drink."

I wish it wasn't necessary for this course of action today to have to be taken at all, but unfortunately it's desperately needed. Fetal alcohol syndrome disorder is the most commonly known cause of mental retardation and is a major health problem. It's important to remember that as the mother consumes alcohol and her blood alcohol rises, the alcohol is freely crossing the placenta and the fetus is being exposed to the same blood alcohol levels—quite a horrifying thought when one considers the size of an adult and the size of the fetus from conception to a full-term delivery, unless they abort or are born prematurely, which is common. The effect of the alcohol on the fetus depends on when and how much alcohol is taken during the pregnancy. The brain is continuing to develop right through the pregnancy, so therefore brain damage is inevitable.

This brain damage, I repeat, is the leading cause of mental retardation. But most individuals with FASD have normal intelligence; they just don't have the ability to use the intelligence they have.

John, whom we adopted at the age of nine days, has only recently been diagnosed at St Michael's Hospital

FASD assessment centre. His life has been chaotic, by any standards, not of his own choosing. The fact that he is here today is not a tribute to the school system. Educational specialists are not trained to recognize the symptoms, and when FASD is diagnosed, there are no special education facilities that can adapt to the special needs of the FASD student. They struggle and stumble, with their self-esteem being battered at every turn.

Professional counsellors, doctors and psychiatrists are woefully inadequate in making the diagnosis, and without a diagnosis the children suffer greatly in the education system without the supports in place that are necessary for them to achieve their potential. The school years will typically be miserable, and during this time the dropout statistics are high. These children often drift into homelessness, prostitution, drug and alcohol problems, and trouble with the law.

As members of the government, you will be horrified at the statistics quoted. During their lifetime, the individuals alive today with FASD will cost the taxpayer about \$600 billion. I believe that figure has probably increased since those figures were quoted in a report from FASworld that I read recently.

In a fact sheet, *Current Perspectives*, which I quote in the paper, it states that it is estimated that each individual with FASD costs the taxpayer \$2 million in his or her lifetime for health problems, special ed, psychotherapy, counselling, welfare, crime and the criminal justice system.

Many can't live independently, and most families can't afford financially to support them. Many have their babies removed from them because they are not able to support them financially or emotionally. There are lots of grandparents who are raising their grandchildren. Relationships are often difficult for them to maintain, so there is separation and divorce and further failure for the FASD person. Employment becomes impossible because of the many stresses in the work environment, which they simply can't handle.

There are times, I know, when most adoptive parents, as much as they love their FASD child, as I do, as Bonnie does, as we all do, feel that they've been taken advantage of by society. Having taken on the huge responsibility of raising an FASD child, we find society offers no help and shows no interest in helping families such as ourselves. The passing of Sandy's Law would be an indication that there are some people out there who care.

Bill 43 is a very small start to solving a very big problem, but it is possible to completely eradicate this devastating problem. It's so simple. We don't know how to prevent cancer or diabetes, but we do know how to prevent fetal alcohol syndrome disorder. Let's make a start, please.

Mr John Stanley: Good morning. My name is John Stanley. I have alcohol-related neurological disorders. It's caused by my birth mother drinking while she was pregnant.

Over the past 27 years, my life has been so far from normal that every day is a challenge for me. In school, I

have had many problems: learning disabilities, making friends, paying attention in class, remembering. I hated going to school each day. All my life I have had problems sleeping. Day and night are reversed for me, meaning that I am often exhausted and irritable because I try to sleep when the rest of the world does.

Changes and surprises are very stressful for me. I tend to become angry when stressed. Depression is a major problem for me. There have been times when I have felt suicidal. Because of this, I am unable to keep a job, and therefore I am currently receiving Ontario disability. This depresses me, that I have to be financed by the government for the rest of my life.

I am on medication to help with my mood and stress and will always need to be on medication.

The bottom line is that anything to help prevent all of this is a good thing.

I would like you to understand that as a result of my mother drinking alcohol while pregnant, I have permanent brain damage, which cannot be treated. It can be helped by the environment and attitude of people around me. Medications can help somewhat with the handling of stress and anxious feelings, but it is permanent brain damage.

Nobody should have to go through what I do, but I suppose I could say I'm one of the lucky ones. Some people with fetal alcohol spectrum disorder are mentally disabled and not able to function in society at all. I have the support of my wife and family, which has made a big difference in my life. But when this sign is designed, please make sure that it's big enough and colourful enough, without too much writing on it, so that it will attract attention. Thank you.

1040

The Chair: Thank you both. Questions?

Mr Marchese: I've got two quick questions. How many people in Ontario do we estimate have the problem of fetal alcohol syndrome?

Ms Buxton: Some 100,000. It's about one in 100.

Mr Marchese: In Ontario, not Canada?

Ms Buxton: In Ontario.

Mr Marchese: The other question I had, and you both could answer it, but maybe for John: Without being critical in what I'm about to say, the government has introduced an idea saying, "We're going to hold students until age 18 by law," as opposed to 16. For someone with fetal alcohol syndrome, unless it's diagnosed—you keep students until age 18 on the basis that somehow we might be able to help them. If we don't diagnose the problem and we hold students for two more years—

Mr Stanley: It's going to make it worse.

Mr Marchese: It's going to make it worse, right?

Mr Stanley: It was very hard for me to go through school. I went to school for 13 years. It felt like I went for 30, because every day teachers would harass me. They'd tell me that I'm stupid, that I don't belong there, there's something wrong with me. In high school I tried to commit suicide because a teacher did that to me. The teacher said, "You know, you're 20 years old. You

should be out of here by now.” I couldn’t take it any more.

Mr Marchese: I understand. Thank you.

The Chair: Thank you. Any more questions? If not, then, John, I also want to commend you for your determination to overcome all these challenges, and I thank May in helping you along the way.

FETAL ALCOHOL SPECTRUM DISORDER GROUP OF OTTAWA

The Chair: I’d like to call on the next group, FASD Group of Ottawa, Elspeth Ross. Welcome.

Ms Elspeth Ross: Thank you. My name is Elspeth Ross. I’m speaking to you today as an educator, as a parent, and also probably as a spouse who lives with FASD 24 hours of every day. My husband thinks that he’s also affected, although this is denied in his family. I have been working locally in Ottawa with a support group in our children’s hospital for the past five years. I work provincially and nationally. I’ve been involved in a fetal alcohol outreach project and in a best practices effort.

I wish to commend you for Bill 43. It’s an important initiative. It’s a very good thing that MPP Ernie Parsons has brought this forward despite tragedy and that you have passed it through second reading, but I would like to make some important points here about this.

Warning signs are only part of a primary prevention effort. Signs are important as part of this, but, like tobacco, everything works together. They’re geared to the population at large. We need warning signs, labels on liquor bottles, limiting of availability, price increases, posters, pamphlets, education in schools, physician instruction. All of this works together.

There’s some best practice evidence to support the warning signs and posters as a means of increasing awareness, but one of the limiting factors is that people simply do not see the message enough. A national study in the US of those exposed to alcohol-in-pregnancy messages found a positive relationship with the number of exposures to multiple message sources, which actually did reduce the drinking level. We haven’t seen these warning signs around Ontario very much. Those of us who work very, very hard in the prevention effort do so without funding. The messages would definitely help us in our efforts. Last week in Ottawa we had a mocktail competition, with pregnant women as judges and five bars competing. But we feel that we’re very much alone. We feel that we could work much more effectively with multiple messages.

We’re pleased and proud that Best Start in Ontario—have you seen these around? They’re supposed to be on the buses; they’re supposed to be around. Some of you are looking puzzled. I have the pamphlets here.

We’re pleased and very proud that Best Start in Ontario has very good resources starting this month of May, but we feel strongly that establishments that sell and

serve alcoholic beverages should have a responsibility to tell people also at the point of sale, at the point of service.

In passing this law to get the signs, Ontario will join other jurisdictions. Have you seen the signs in the city of Toronto? I’ve seen them in women’s washrooms. The message: “Warning. Drinking beer, wine or spirits during pregnancy can harm your baby.” It may be only in the women’s washrooms, but the city of Toronto is one place. I’ve given you the municipal bylaw in your package. The town of Wawa, municipalities in BC, 21 states in the US, cities in the US and countries like Brazil, Columbia, Ecuador, South Korea, Mexico and Zimbabwe have these signs. You will join these other jurisdictions around the world.

I have two points here that I think are very important about wording. The bill at the moment says, “fetal alcohol syndrome.” This is the old term and it does not apply to my family. It has been superseded. It requires the small stature, the facial features, the mental challenges. My boys, my family, most of them—fetal alcohol syndrome is the tip of the iceberg. It’s fetal alcohol effects: ARND, alcohol-related neurological disorder. That’s the term for the other ones. It’s a spectrum. That’s why we use the new term “fetal alcohol spectrum disorder.” It’s an invisible disability.

Our sons are fetal alcohol affected. They’re not small. They don’t have the face. They’re of average intelligence. They graduated from high school—in the old days, they were able to do that—and the older one from a community college in aboriginal studies. They’re both working. The older one has a learning disability. His wife is his external brain. She helps him with the things he can’t do. Our younger son found a job through an Ontario disability support program, assisted employment. He’s keeping his job with difficulty. He has problems with learning, remembering, thinking things through, acting impulsively, staying out of jail, getting along with others, math and money.

The wording in the bill “developmentally handicapped” and “a reduced lifespan” does not apply to my family. You have the power to change that. We don’t like the term “handicapped.” But phrases like “birth defects” and “brain damage” cover everything.

We should not just be cautioning pregnant women. Women of childbearing age should be cautioned and their drinking partners. We need to caution the men they drink with.

My last point is very important. The wording of the sign, as you have it now, engraved in legislation, please take it out of there and put it in your regulations, as you were saying, so that it can be altered. As it is now, it’s too long, it’s repetitive, it’s complicated and it’s misleading. I’m sorry to say that rather bluntly. It’s not good wording, because what we should have is something tested. Best Start has had focus groups, and the wording has been tested by these people. What I would suggest to you is simply the wording that’s used in this material: “Drinking alcohol during pregnancy can cause permanent birth defects and brain damage to your baby.” Let’s start

out with that wording and get a committee from the FAS community with Best Start to provide input into the wording.

I would also suggest that you look at the size of words. In the bill now, it talks about the size of the sign, but you could have words this big in a sign. I think you need to specify the size of the letters, as Arizona did in their sign. Also, where is the sign going to be? It could be put down the back hall in the establishment. You might want to think about that. It should be at the point of sale.

My recommendations are about making changes to the bill: “fetal alcohol spectrum disorder” instead of “syndrome,” and change the wording, please, to be more effective for all of us. You have the power to change the words.

You have the power to pass the bill. We need treatment, we need diagnosis, we need treatment for pregnant women, we need support, we need funding, we need lots of things. But a short, simple message that’s widely seen would really help us.

1050

The Chair: Thank you, Elspeth. Mr Marchese has a question for you.

Interjection.

Mr Marchese: That’s what reminded me of the question I’m about to ask. I’m assuming that Mr Parsons is dealing with some of the points you made and some of the changes. That’s good, so we don’t have to deal with that.

What I’m reminded about is how little we know about so many problems. My father died of Alzheimer’s disease and, before that, I paid no attention to the problem whatsoever. It seems that we only pay attention when we’re affected by something.

Ms Ross: That’s right.

Mr Marchese: So unless we seriously deal with this problem in the way that many of you have suggested, we’re going to continue suffering from this. If indeed it’s 100,000 people, if that’s a good best estimate, this is serious in terms of the effects it has on us all. So we have to do a better job, it seems, based on what you’re saying.

Ms Ross: We have to do a better job with multiple messaging. In the case of tobacco, in the case of heart disease, we are doing that. We’re having an impact. We have to start doing this now.

Mr Marchese: And I agree with your wording. It carries an image much more easily than something that is a little more abstract and complicated to understand.

Mr Mario Sergio (York West): Could we have copies of those?

Ms Ross: They’re all here. The copies are here. Please take them.

We have to normalize what it is to have fetal alcohol. It’s all around. It’s in my family. It’s in previous generations. It’s probably in some of your families. But we have to normalize it. But our concern is that this problem is not going away. It’s not somebody else’s problem. It’s not an aboriginal problem. It’s all around the world. The highest rate is in South Africa, where people were paid in

wine. It’s everywhere, and it’s getting worse, because women are binge drinking more and more. The publicity is incredible, with low-carb and all this stuff now in terms of media messages about how it’s cool to drink. We are really concerned that the messages are not getting out to young women of child-bearing age. Please do something about the wording. You’re the power with the wording.

The Chair: Thank you, Elspeth. You’ve given us good input.

FASWORLD TORONTO

The Chair: The next group is FASworld Toronto, Mary Cunningham. Welcome, Mary.

Ms Mary Cunningham: Good morning. My name is Mary Cunningham and I’m the president of FASworld Toronto. I strongly support Bill 43, and I commend Mr Parsons for bringing it forth at this difficult time. This is the first positive public step for FASD prevention that’s happened in Ontario.

I’m here to suggest some other low-cost, ready-to-implement strategies to follow this bill to help eliminate FASD. Also, my own story will illustrate why the term FASD, not FAS, is critical.

In June 2003 I retired from 30 years of secondary school teaching. I was a teacher, a department head, an ed consultant. I got the curriculum rolling, I co-authored a textbook, and had executive roles on two of the Ontario family studies organizations.

I’m really pleased with my career except for one thing, and that’s basically why I’m here today. My two roles, as FASworld president and the co-founder of OCMPE, which is the Ontario Coalition for Mandatory Parenting Education, happened for a reason. They happened when my family life and my professional life collided. They collided very shortly after the publishing of this article by Bonnie Buxton, which details Colette’s story. It was in Reader’s Digest of March 2000. I read this one Friday night, and so did my husband, who’s also a teacher. We knew, just like a lightning bolt had struck us, what was wrong with our second child. She joined our family as a young baby, at the age of three months.

We knew something was terribly wrong. She’d dropped out of grade 10 by this point. Educationally, she had achieved almost nothing and created enormous problems for the administrators and teachers in two high schools. She does not acknowledge or discuss her almost certain FASD, but we recognized the usual signs: serious school truancy, resulting in indefinite suspensions; shoplifting; assaults; police and court involvement; depression; refusal to work; wild partying; and drug and alcohol abuse. Think of anything you would not want your teenage daughter to do—I mean, anything.

She was miserably unhappy, and so were we. I think we both went to work for a rest in those days. In elementary school, they assured us she was fine. We’re both teachers; we knew something was wrong. We knew something was wrong with her educational success, be-

cause she just wasn't getting it. So we had her privately tested and she had profound learning disabilities, despite the fact that the school didn't realize it.

The wheels that squeaked in elementary school absolutely fell off in high school, and that is when the dramatic behaviour changes really started. Our child was every parent's and every teacher's nightmare. It was so bad that at age 17 we had to ask her to leave our house. We couldn't cope with it any longer. We did support her as external brains and with massive amounts of money, but seven years later she's had a variety of unusual occupations, five abusive domestic relationships, at least four of which were with another person we have identified as probably having FASD—it is really common—a court case and a peace bond, a baby and an enormous amount of help from us.

She has a baby, as I said. Our gorgeous baby grandson was born in a clean pregnancy. As far as we know, he's going to be fine. We've gotten rid of all the abusive boyfriends, at least for now, but we're holding our breath. Research shows that her outlook is grim. We know we're on a roller coaster. The chances that she will ever be completely independent with a job, with a T4—this is our great ambition—are slim. She is costing you a fortune, and she's costing me a fortune because I'm a taxpayer too. Wonder where your deficit is coming from? Look here.

As FASworld president and a teacher, I now recognize that the story I've just told you is absolutely classic, textbook, undiagnosed FASD. All the physical signs of FASD, such as heart defects, scoliosis, dental and inner-ear abnormalities, that would show clearly in a FASD individual are not obvious. People do not understand that she has permanent brain damage that will make her behaviour totally unacceptable from time to time. Instead, she will be arrested, strip-searched and humiliated. This has already happened.

When I understood FASD, I then understood my only real regret from teaching, and that's one of the main reasons I'm here today. I knew why I had failed to reach or teach dozens and dozens of students during my career. These are the students who score very poorly on the grades 3, 6, and 9 standardized tests. They fail the grade 10 literacy repeatedly—it doesn't matter how many times they do it—and they categorically cannot do math—all three mandatory credits of it. On top of this, they cannot sit still and they tend to drive their teachers crazy with class-control problems. But think about it. These students are profoundly disabled. It's not that they won't behave; they can't. And this is absolutely crucial. You have to understand this—it's not that they won't; they can't.

In 1998, I didn't have any teaching strategies that worked, but fortunately western Canada is light-years ahead of us in the FASD department. Since retiring, I've made a study of what will work and can now teach teachers strategies that will probably work for their students with FASD. The bad news is that they are expensive and challenging. The good news is that students with FASD can learn and be successful—

absolutely. As a teacher who knows the system, I will be presenting these strategies at four conferences in the next several months. As a family studies teacher, I immediately started to do a lot of FASD prevention education in my grades 11 and 12 parenting classes. I think several of my students then knew that being the way they were wasn't their fault. I could tell. We never talked about it, but you can tell. This was one lesson that was never, ever interrupted. They recognized themselves or others. They came up after class and talked to me.

I have continued these FASD education and parenting classes around the Toronto area and I know it works. After 30 years of teaching, I know when I score. I can teach other teachers how to do this. Other teachers in the family studies community are very prepared to do this. This is one lesson that sticks. I know that every time I do a parenting class, I prevent at least one FASD birth. That saves you and me about \$2 million. This is pretty good pay for 75 minutes' work. We must make students understand that no alcohol is safe in pregnancy before they make alcohol a regular part of their lives. I am morally certain that if we can get this message out to all senior high school students before the legal drinking age—that is absolutely crucial—we can dramatically reduce FASD rates in Ontario and Canada. People who are legal drinkers do not absorb this message that no alcohol is the best way. They don't absorb it as easily. The grade 11 and 12s get it. They younger ones are not quite old enough to get it.

The only problem is that only 10% of students in Ontario take parenting right now. This is why it must move to the list of mandatory credits in Ontario. The family studies teachers of Ontario have been working on this for 14 years. We know it'll work. We know that a mandatory parenting credit in Ontario will help reduce a host of social problems, such as teen pregnancy, child abuse and neglect and domestic abuse, in addition to FASD. Sadly, most of those conditions are also connected to the high rates of FASD. We have worked since the early 1990s to make parenting mandatory. We have wide public support for OCMPE; we just can't get into the minister's office to explain it. I'm leaving our vision statement in your package handout. OCMPE will do more than prevent FASD, but this is the step that will work.

What I'm recommending is to make one senior parenting course mandatory for graduation in Ontario. Senior students are mature enough to get this message and pass it on; younger students aren't. The infrastructure to do this is ready to roll and family studies teachers are well organized to do this. You, the members of the Ontario Legislature, however, have to make the changes that will make this happen.

Secondly, infuse FASD prevention into salient parts of the existing K to 12 curriculum outside of parenting courses. Remember that this is only a Band-Aid and it will not do the whole job, because the students are too young to get the full message. Suggested hot points, in my opinion, are grades 6 to 8 pregnancy prevention efforts and the grade 9 mandatory physical and health

education course. Any other infusion of FASD information must not be superimposed on the current crowded curriculum just willy-nilly; it has to be respectful of the education expectations it uses.

1100

The Chair: Sorry for the interruption. You've exceeded your time limit, so please wrap up.

Ms Cunningham: OK. FASD information will also fit well into your Roots of Empathy and character-building programs. Help teachers find out about FASD and consider the students with FASD, please.

The Chair: Any questions for Mary?

Mr Marchese: There are many, but just one, because we're running out of time. You have a lot to say, but, as a teacher, you're familiar with the Safe Schools Act?

Ms Cunningham: Yes.

Mr Marchese: You probably also will admit or recognize that a lot of these students who have this syndrome would be affected by the Safe Schools Act.

Ms Cunningham: Absolutely. Our students, our individuals, are thrown out all the time.

Mr Marchese: New Democrats attacked the government when they introduced it and so did Liberals. I'm not quite sure we're pushing the minister enough to realize that this is a serious problem. Would you have a suggestion for Mr Parsons and the Liberal caucus in terms of what they should do with the Safe Schools Act as it relates to these students?

Ms Cunningham: Honestly, I like what I'm starting to hear now from the minister with respect to it.

Mr Marchese: So you like that?

Ms Cunningham: I like the fact that they're looking at it and they're starting to understand that students with disabilities are being thrown out in disproportionate numbers. I think we'll get there.

Mr Marchese: Oh, I'm glad you think he said that, because I haven't heard it, but that's good. We're working on that. Thank you.

The Chair: Thank you, Mary.

We have now finished with all the deputations and we're going to be proceeding with clause-by-clause consideration of Bill 43. Any comments, questions or amendments to any section of the bill and, if so, which section?

Mr Parsons: I would like to move that, notwithstanding the committee's order dated Wednesday, May 12, 2004, amendments be accepted through the course of clause-by-clause consideration of Bill 43.

The Chair: Discussion?

Mr Marchese: Just some general comments before we move into the amendments. I just wanted to thank all the deputants for coming. They made a lot of useful suggestions. Not to be critical of the Liberal government, but I think they have to remember that change won't happen by itself, Mr Parsons.

Mary, you can make statements of your own if you like. Nobody's preventing you from doing it.

We thank Mr Parsons for having introduced this bill, because it's important, but it leaves it open to address

many other questions they have raised, which I'm sure Mr Parsons is very knowledgeable about. My point is that we need to press government. It doesn't matter who it is. It could be a Liberal government, a Conservative government or NDP, it doesn't matter. Changes only happen where there is pressure. That's all I wanted to say to you. You mustn't simply believe that this first step is a corollary of what will happen, because it won't unless all of you keep on reminding the government in particular and using the opposition parties to help with that cause.

The Chair: Mr Parsons has made a motion. Any debate on that motion? If not, are we ready to vote on that motion? All in favour? Opposed, if any? That is carried.

Mr Parsons: Before I move the amendments, I'd like to make a comment. This bill was conceived on a drive home from Florida alone. I put the legislation forward knowing that my belief that none of us is as smart as all of us would come true again. That's my sense with this.

To put it in perspective, when we had Sandy join our family, FASD simply wasn't known. We knew these were kids with behaviour problems, that kids got in trouble with the law, and if you loved them harder and if they worked harder in school—we didn't know what it was. We've made a lot of progress in the last 20 years but we haven't yet reached where I think we as a society are capable of reaching.

I'm going to move amendments that virtually amend every clause that is in it. I believed that was going to happen, because I wanted to hear—and I do appreciate this.

In addition to the groups that appeared today, I probably have received 600 or 700 e-mails and letters of support from the Ontario Hospital Association and virtually every health unit in municipalities. There's a real will to make it work. The comments made by every one of the presenters today are very legitimate.

The amendments are going to change a lot of what was in the bill to regulation. That will allow for changes. I'm not sure yet that we've captured the right wording for the sign. I'm not sure the wording that's right today will be the right wording five years from now. So, if I could move a series of amendments, I think it will make the bill more flexible.

What is the right size and colour for the sign? That may be different for the type of restaurant or for the location. I want to provide the flexibility. Certainly there will be a minimum font size, but where a bright red sign may work in one restaurant, a bright blue or brown or whatever one might be better in another restaurant to make it stand out. I appreciate the advice given to me over the last few weeks.

I would like to move that subsection 30.1(1) of the Liquor Licence Act, as set out in section 1 of the bill, be struck out and the following substituted:

“Requirement to display sign

“30.1(1) No person shall sell or supply liquor or offer to sell or supply liquor from a prescribed premises unless:

“(a) the premises prominently displays a warning sign containing the prescribed information that cautions women who are pregnant that the consumption of alcohol during pregnancy is the cause of fetal alcohol syndrome;”

I don't know if I can amend an amendment, I would like to make fetal alcohol “syndrome” “spectrum disorder.” If you would support what I've read rather than what's written, it will be “fetal alcohol spectrum disorder.”

“(b) the sign is posted at the premises in accordance with the prescribed criteria; and

“(c) the sign satisfies any other criteria that are prescribed.”

The Chair: Thank you, Mr Parsons. We will proceed section by section. Any debate on this amendment? All in favour? Opposed, if any? That is carried.

Mr Parsons: I'm looking for guidance from the Chair. Should we read and move section 1 of the bill or should I just do the amendments?

The Chair: Do the amendments first.

Mr Parsons: OK, thank you.

My second amendment is, I move that subsection 30.1(2) of the Liquor Licence Act, as set out in section 1 of the bill, be struck out and the following substituted:

“Language of sign

“(2) A sign under subsection (1) shall be in English and may be in any other language that is prescribed.”

The Chair: Any debate on this amendment? If not, all in favour? Opposed, if any? That is carried.

Mr Parsons: The next amendment is, I move that section 30.1 of the Liquor Licence Act, as set out in section 1 of the bill, be amended by adding the following subsection:

“Regulations

“(2.1) The Lieutenant Governor in Council may make regulations,

“(a) prescribing premises and types of premises that are required to display a sign under subsection (1);

“(b) governing signs for the purpose of subsection (1);

“(c) prescribing languages, other than English, which may be used on a sign for the purposes of subsection (2) and specifying areas of the province where signs in a prescribed language may be displayed.”

The Chair: Any debate on this one? If not, then all in favour? Opposed, if any? That is carried.

Mr Parsons: The final amendment is, I move that section 2 of the bill be struck out and the following substituted:

“Commencement

“2. This act comes into force on a day to be named by proclamation of the Lieutenant Governor.”

The Chair: Any debate on this amendment? If not, then all in favour? Opposed, if any? That is carried.

Any further amendments?

Mr Gerry Martiniuk (Cambridge): If I may suggest, Mr Parsons, we should amend the explanatory note and the title of the act to reflect the change we've discussed and made in regard to the name.

Mr Parsons: Thank you. Excellent.

The Chair: Would you like to make the amendment, Mr Parsons, or, Mr Martiniuk, would you like to make that amendment?

Mr Martiniuk: No, I would like Mr Parsons to make that.

Mr Parsons: I would move that the explanatory note be amended to conform with—

Mr Albert Nigro: Excuse me, I wonder if I could address the members of the committee. My name is Albert Nigro. I'm legislative counsel. The explanatory note was written by my office, it was written by me, and I will amend the explanatory in my office as a matter of editorial policy to reflect the amendments made at the committee, so there's no need for a motion for that.

Mr Parsons: Thank you.

The Chair: What about the title? Do we need—

Mr Nigro: You would have to make a motion to amend the long title if you wanted to do that.

The Chair: So you will make that motion, right, Mr Parsons?

Mr Parsons: Yes. The amendment I'm making then is to change the title from “fetal alcohol syndrome” to “fetal alcohol spectrum disorder.”

The Chair: Will we get that in writing?

Mr Parsons: Do I have to write it?

Interjection.

Mr Parsons: You will? Thank you.

The Chair: Any debate on this? All in favour? Opposed, if any? That is carried.

Any further amendments?

If not, then are members ready to vote on the bill, as amended?

Any further debate?

Shall section 1, as amended, carry? All in favour? Opposed, if any? That is carried.

Shall section 2, as amended, carry? All in favour? Opposed, if any? That's also carried.

Shall section 3 carry? All in favour? Opposed, if any? That's carried.

Shall the short title, as amended, carry? All in favour? Opposed, if any? That's carried.

Shall Bill 43, as amended, carry? All in favour? Opposed, if any? That's carried.

Shall I report the bill, as amended, to the House? All in favour? Opposed, if any? That is carried.

The meeting is adjourned. I want to thank all the participants for coming forward to help us with that. I especially want to thank Mr Parsons for the bill.

The committee adjourned at 1111.

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