Legislative Assembly of Alberta

The 28th Legislature
First Session

Standing Committee on Families and Communities

Bill 204
Irlen Syndrome Testing Act
Public Presentations

Wednesday, September 25, 2013
1:01 p.m.

Transcript No. 28-1-17

Legislative Assembly of Alberta
The 28th Legislature
First Session

Standing Committee on Families and Communities

Quest, Dave, Strathcona-Sherwood Park (PC), Chair
Forsyth, Heather, Calgary-Fish Creek (W), Deputy Chair

Brown, Dr. Neil, QC, Calgary-Mackay-Nose Hill (PC)
Cusanelli, Christine, Calgary-Currie (PC)
DeLong, Alana, Calgary-Bow (PC)
Fraser, Rick, Calgary-South East (PC)
Fritz, Yvonne, Calgary-Cross (PC)
Goudreau, Hector G., Dunvegan-Central Peace-Notley (PC)
Jablonski, Mary Anne, Red Deer-North (PC)
Jansen, Sandra, Calgary-North West (PC)
Jeneroux, Matt, Edmonton-South West (PC)
Khan, Stephen, St. Albert (PC)*
Kubinec, Maureen, Barrhead-Morinville-Westlock (PC)**
Leskiw, Genia, Bonnyville-Cold Lake (PC)
Luan, Jason, Calgary-Hawkwood (PC)***
Notley, Rachel, Edmonton-Strathcona (ND)
Pedersen, Blake, Medicine Hat (W)
Swann, Dr. David, Calgary-Mountain View (AL)
Towle, Kerry, Innisfail-Sylvan Lake (W)
Wilson, Jeff, Calgary-Shaw (W)
Young, Steve, Edmonton-Riverview (PC)

* substitution for Neil Brown
** substitution for Matt Jeneroux
*** substitution for Steve Young

Bill 204 Sponsor

Jablonski, Mary Anne, Red Deer-North (PC)

Support Staff

W.J. David McNeil	Clerk
Robert H. Reynolds, QC	Law Clerk/Director of Interparliamentary Relations
Shannon Dean	Senior Parliamentary Counsel/ Director of House Services
Philip Massolin	Manager of Research Services
Stephanie LeBlanc	Legal Research Officer
Sarah Leonard	Legal Research Officer
Nancy Zhang	Legislative Research Officer
Nancy Robert	Research Officer
Corinne Dacyshyn	Committee Clerk
Jody Rempel	Committee Clerk
Karen Sawchuk	Committee Clerk
Christopher Tyrell	Committee Clerk
Rhonda Sorensen	Manager of Corporate Communications and Broadcast Services
Jeanette Dotimas	Communications Consultant
Tracey Sales	Communications Consultant
Janet Schwegel	Managing Editor of *Alberta Hansard*

Transcript produced by *Alberta Hansard*

Standing Committee on Families and Communities

Participants

Alberta College of Optometrists FC-325
  Gordon Hensel, Registrar
  Margaret Penny, Past President

Canadian Association of Irlen Professionals FC-330
  Judy Pool, Vice-president
  Nola Stigings, President

Alberta Medical Association FC-335
  James Lewis, Section of Ophthalmology
  Ian MacDonald, Section of Ophthalmology
  Lyle Mittelsteadt, Senior Medical Adviser
  Raphael Sharon, President, Section of Pediatrics

Sharon Vaselenak FC-339

Alberta School Boards Association FC-342
  Jacquie Hansen, President
  Colleen McClure, Associate Superintendent of Student Services, Greater St. Albert Catholic Schools

Irlen Institute International Headquarters FC-346
  Helen Irlen, Executive Director
  Sandra Tosta, Vice-president of Business Development and Research Operations

1:01 p.m. Wednesday, September 25, 2013

[Mr. Quest in the chair]

The Chair: Good afternoon, everybody. I'd like to call the meeting to order, so if everybody can take their seats. Welcome to all the members and staff in attendance for today's meeting of the Standing Committee on Families and Communities.

I ask that the members and those joining the committee at the table introduce themselves for the record. We'll go around the table first, and then we will go to the telephones. A number of our members are teleconferencing in today. With us not being in session, our members tend to be in their constituencies or on other duties around the province but, again, will be joining us via teleconference. We'll start with introductions, going around the table this way.

Ms Zhang: Nancy Zhang, legislative research officer.

Ms Leonard: Sarah Leonard, legal research officer.

Ms Robert: Nancy Robert, research officer.

Mr. Goudreau: Good afternoon. Hector Goudreau, MLA, Dunvegan-Central Peace-Notley.

Mrs. Towle: Kerry Towle, MLA, Innisfail-Sylvan Lake.

Mrs. Leskiw: Genia Leskiw, MLA, Bonnyville-Cold Lake.

Mrs. Jablonski: Good afternoon, everyone, and welcome. Mary Anne Jablonski, MLA, Red Deer-North.

Ms Cusanelli: Good afternoon. Christine Cusanelli, Member for Calgary-Currie.

Mrs. Fritz: Good afternoon, everyone. Yvonne Fritz, MLA, Calgary-Cross.

Dr. Massolin: Good afternoon. Philip Massolin, manager of research services.

Mr. Tyrell: Good afternoon. Chris Tyrell, committee operations.

Ms Rempel: Jody Rempel, committee clerk.

The Chair: Dave Quest, MLA for Strathcona-Sherwood Park and chair of this committee.

If we go to the phones, whom do we have on the phones with us?

Ms Kubinec: Maureen Kubinec, standing in for Matt Jeneroux.

The Chair: Thanks, Maureen.

Mr. Luan: Jason Luan, standing in for Steve Young.

Dr. Swann: David Swann, Calgary-Mountain View.

Mr. Pedersen: Good afternoon. Blake Pedersen, Medicine Hat.

Mr. Wilson: Jeff Wilson, MLA, Calgary-Shaw.

The Chair: Very good. Great. All right. Well, thank you, and welcome again.

You should all have a copy of the agenda. I would like to get a member to move adoption of the agenda, please. Mr. Goudreau. All in favour? Everybody good on the phones? Great. Thank you.

There are a couple of housekeeping items to address also. The microphone consoles are operated by the *Hansard* staff, so you don't have to do anything with those. If you can keep your cellphones and BlackBerrys off the table; they can interfere with the audiofeed. Audio of these committee proceedings is streamed live online and recorded by *Hansard*, so everything will be on the record.

You should all have the minutes from our meeting of July 22 of this year. Unless there are any errors or omissions, then I need a motion to approve the minutes of the July 22 meeting. Mary Anne. All in favour? Everybody is good on the phones? Thank you. That is approved.

Okay. Then we're going to go to the presentations on Bill 204, the Irlen Syndrome Testing Act. Further to the decision made by the committee at our last meeting, we have six presenters organized today. We have half an hour set aside for each presenter, which includes up to 15 minutes of presentation time, followed by the opportunity for committee members to ask questions. To ensure that all of our guests are treated fairly and that we are able to proceed in a timely fashion, I'll be asking the committee clerk to use the timer to keep us on track this afternoon.

I'd like to ask our first presenters, representing the Alberta College of Optometrists, to join us at the table and begin your presentation when you're ready. Is the college here? Very good. Just take a minute to have a seat, get comfortable, and get ready.

To our members that are on the phone, if you have questions, if you could e-mail those to the clerk, please, so we can keep them in order. We don't want to miss anybody.

Again to our presenters, the microphones are operated by *Hansard*. You don't have to do anything with those. The meeting is open to the public, as you can tell, and recorded by *Hansard* and streamed online.

With that, I will get the two of you to introduce yourselves, please. Start whenever you're ready.

Alberta College of Optometrists

Dr. Hensel: Well, good afternoon, and thank you, Mr. Chairman. I have to apologize for my voice. It's a little hoarse. Are you all able to understand me? Okay. The slides are projected behind you, so I'm not sure if you want to move your chair or just listen.

Anyway, we would like to thank you very much for the opportunity to address you today. My name is Dr. Gordon Hensel. I'm the registrar for the Alberta College of Optometrists. Joining me today is Dr. Margaret Penny, who is a past president of the Alberta College of Optometrists. Dr. Penny also has the unique distinction of holding a master's degree in education, specializing in reading and learning disabilities. This unique dual education provides her with an extraordinary ability to discuss children's vision and reading and learning disorders from the viewpoint of an eye doctor and an educator.

We'd like to set the record straight. The Alberta College of Optometrists believes that all children deserve the best educational, societal, and health care opportunities that will allow them to achieve their potential. Bill 204 does not accomplish this, nor will any amendment to Bill 204 accomplish this. The ability to see clearly and comfortably and to comprehend and integrate what we have learned involves a multitude of factors, and having children look through a tinted lens does not address any of the factors. To understand whether looking through a tinted lens can actually impact a child's ability to read and learn, we have to understand what factors impact a child's ability to read and learn, so I'd like to take a few moments and go through these factors.

The first one is vision. We know that 80 per cent of all sensory information to the brain comes to us through the eyes. Therefore, vision is on the top of the list. Now, vision involves the ability to see clearly and comfortably, which is what prescription glasses do, but it also involves the ability to move the eyes in all directions, the ability to focus on objects at different distances, and the ability to process and interpret that information.

The next factor is the other senses of hearing, taste, smell, and touch, and they account for the remaining 20 per cent of sensory information processed by the brain. A deficiency in any of these areas can also have a serious impact on a child's ability to learn.

Next on the list is our general health. Medical conditions and disorders such as attention deficit disorder, metabolic disorders, neurological disorders, and others too numerous to list can also affect a child's ability to learn.

Next is what we'll call home life and school environment, and this involves many different things. It involves whether a child lives in a loving and caring home. Was the child read to when they were a child? Do they receive nutritious meals every day? Do they have adequate support in the classroom and school district?

Reading at home on a daily basis is extremely important. Often parents aren't aware that they should be reading with their child on a daily basis, and it is only after a teacher mentions that the child is experiencing difficulties reading that parents start to take a more active role in the child's education. Personally, I think this is one of the big factors for Irlen, that once a child has been singled out for not achieving what they should, the parents do take a more active role, and that may be some of the effect that we attribute to Irlen lenses.

1:10

Finally, there are miscellaneous other factors. These are small, insignificant miscellaneous factors rounding out the list. Now, you'll notice that testing for Irlen syndrome is nowhere to be found on the list. The reason is that Irlen syndrome, if it actually exists, is so far down on the list of factors that may influence reading and learning that it does not even make our miscellaneous category.

Now, we realize that this committee has been inundated with anecdotal stories, personal opinions, and research papers extolling the virtues of Irlen lenses. These stories and opinions are found to lack accepted scientific research modalities and proof.

I would now like to call upon Dr. Penny to explain how vision and learning are closely interrelated. During her presentation you will notice that the vast, vast majority of alleged signs and symptoms of Irlen syndrome are, in fact, common vision problems diagnosed and treated every day by ophthalmologists and optometrists following a complete eye examination.

Dr. Penny: Thanks, Gord. The components of the visual system. The visual system may be broken down into a number of component areas. These include refractive status, ocular motility or tracking, accommodation or focusing, binocularity and eye teaming ability, visual perception and processing, and eye health. I will be briefly discussing only the first four areas as they have the greatest impact on reading and learning.

The first area most people think of in regard to vision is how well a person sees, the 20/20 measurement of eyesight. While a child must be able to see the board and his books reasonably well, for the most part this area does not have the greatest impact on learning unless the child is far sighted with focusing difficulties.

If you could all take a look at the screen, this slide shows the work from a grade 2 student in my practice. She had eye strain, headaches, blurred vision when reading, all signs of Irlen syndrome, yet she was actually just far sighted with focusing difficulties and needed reading glasses.

If you look at the initial sentence copy, there are many reversals of letters, incorrect copying of the words, and poor spacing of the words and letters. In the bottom sentence copy she had been wearing her reading glasses for just a month. Notice the dramatic changes. Her work demonstrates how correcting far-sightedness can have a dramatic effect on the processing of visual information.

In sports the ability to follow a ball in a smooth fashion and, when reading, the ability to fixate from one word to the next are two examples of tracking skills. If a child's eyes are moving in a jerky or erratic manner, he will be unable to keep his place with just his eyes, so he will use his finger to follow. Signs of tracking difficulties include having to use your finger to keep your place, skipping small words or endings, or losing your place frequently when reading or rereading lines. If a child skips over a small word, realizes it, then he may read the word backwards. Word reversal such as "on" and "no" or "was" and "saw" are indicators of tracking difficulties as well.

Focusing skills, or accommodation, is the ability to make the visual image clear. In the classroom you must be able to shift your focus quickly and accurately. You must be able to sustain your focus for long time periods, whether you're reading, working on a computer, or doing desk work. Signs of focusing difficulties include holding your book very close when reading; copying slowly from the blackboard, with frequent mistakes; visual discomfort when reading, including rubbing the eyes, tearing, and headaches. Other signs include blurred vision when reading or blurred vision in the distance after doing extended periods of close work.

Binocularity, or eye teaming ability, is a very crucial area of the visual system. If a child does not gain the skill and unity of full eye co-ordination, it will affect his judgment of spatial orientation, depth perception, and, most importantly, clear, single, comfortable vision. A child with binocular problems may complain of eye strain, fatigue, headaches, double vision, or words moving on the page.

When we read, the eyes must converge and focus on a book. The word is scanned by the eyes, and then the word is either drawn from visual working memory or decoded. The eyes then make a short saccadic movement to the next word, and this process continues until the end of the sentence, at which point the eyes make a return saccadic movement to the beginning of the next line.

The signs of Irlen syndrome are, in fact, signs of common vision problems, remediated with traditional methods such as prescribing glasses, prisms, and orthoptics. All colour does is impact on attention, similar to using a highlighter when you're taking notes.

Our written submission covered many concerns with Bill 204. We would like to further speak to some of these points. The first one is academic concerns. Although you've received many anecdotal reports and studies that support Irlen testing and treatment, there is a dearth of independent, peer-reviewed, well-controlled research to corroborate these findings.

Irlen lenses are not new. They came to Alberta over 30 years ago. At that time they were evaluated by the Calgary Learning Centre and the two school boards in Calgary. They failed at that time to show any lasting or significant changes in reading performance and fell by the wayside.

Dr. Hensel: We also have some financial concerns as the cost of an Irlen screening is about five times the cost of an eye exam by an optometrist or an ophthalmologist. A comprehensive eye exam assesses the refractive status, tracking and focusing ability, binocularity, and overall health of the eye and visual system. The signs and symptoms listed for Irlen syndrome are the exact same signs and symptoms of common vision conditions and disorders.

I have given Jody a one-page handout that lists all these symptoms and signs as compared to what we find in eye exams, and I think she'll circulate that afterwards. Mandating that all children who exhibit these signs and symptoms be recommended for Irlen testing is an extreme waste and inefficient use of dollars and actually will be a redundancy to the current services offered by optometry and ophthalmology. Now, we are not asking you to make eye exams mandatory for all children, nor are we asking you to make Irlen testing mandatory for all children.

Regulatory concerns is probably the biggest one for our college. Irlen screeners are not legislated or regulated in Alberta. As such, the Alberta government will not have any control over the screening and treatment process, the annual reassessment, standards of care, or possible future fee increases. As a regulatory college proclaimed under the Health Professions Act, the Alberta College of Optometrists is mandated to protect and serve the public interest. Bill 204 is the antithesis of this mandated protection. In fact, it is not even prudent to allow an independent foreign business complete control over our children with or without any regulatory control.

Dr. Penny: We have a Canadian concern. Following an Irlen screening the only accepted treatment is to purchase the glasses directly from the Irlen Corporation in California at a significant cost to the patient. In fact, did you know that the cost of Irlen tinted lenses is astronomically higher than equivalent glasses purchased here in Alberta? While lens tints are manufactured by a number of companies in the world, light transmissions are standard in the optical industry throughout the world. The Irlen Corporation holds their formula secret and will not share this with the scientific community.

The ACO supports freedom of choice for all Albertans and supports Canadian industry. To mandate in legislation the purchase of glasses only from a U.S. company is both highly unethical and unacceptable for Alberta residents. It totally removes the patient's freedom of choice of provider, a principle that the ACO supports, and one that this government has endorsed for decades.

We have a referral concern. Many of the school boards in Alberta have a policy in place that prevents teachers from referring to specific individuals or professionals for any type of assessment or treatment. I know this to be a fact from working over 30 years with both school boards in Calgary. Bill 204 violates these policies and would put the teachers in a no-win situation of having to decide whether to follow provincial legislation or their school board policy. As school boards support freedom of choice for their students, we also agree with their policy.

1:20

Dr. Hensel: In conclusion, the Alberta College of Optometrists has many serious concerns with Bill 204: the research has not been validated by independent researchers utilizing scientifically accepted methods; the effects of the treatment have been recognized as transient; the screening and treatment costs are astronomical; the Alberta government will not have any control of standards of care, regulation of the process, or possible future increases; and clients will not have any choice in the supplier of their recommended treatment. The Alberta College of Optometrists supports a scientifically based, multidisciplinary approach to both health care and education. Bill 204 does not accomplish this. Our children deserve every opportunity to become lifelong learners who are able to achieve their potential. Bill 204 is not in the best interest of Albertans, and we respectfully request that it be removed from the Order Paper.

Thank you.

The Chair: All right. Thank you for your presentation, Dr. Hensel, Dr. Penny.

I'd like to welcome Ms Notley as well as Rob Reynolds, the Law Clerk, to the meeting.

We have a couple of questions. Again, if you're on the phones, let us know if you have questions for the College of Optometrists. First question, Mrs. Jablonski.

Mrs. Jablonski: Thank you very much, Mr. Chair. First of all, I'd like to thank you, Dr. Hensel and Dr. Penny, for being here and giving us what I believe is your very well-intentioned presentation, but on behalf of the many hundreds of parents whom I've interviewed and discussed this problem with about their children, I would like to say that your comments are extremely insulting to them, referring to the fact that they need a more loving environment, that they need more involved parents. We have parents that are sitting behind you that spent over $150 an hour for visual therapy for 10 months and never saw any benefit from that. I think that you should check your facts before you make comments that insult parents that have worked so hard to do what they can for their children.

Now, Dr. Hensel, we had a discussion about Irlen and Bill 204, and I totally agree with you when you say that every child should have a complete and comprehensive eye exam. I would say that was elementary, myself, so I do agree with that. I understand that one of the first questions that an Irlen screener will ask is: have you had a complete and comprehensive eye exam?

I found it very interesting last night at the town hall meeting in Red Deer. Dr. Charles Boulet, who is a developmental optometrist, commented that not all optometrists are capable of doing a complete and comprehensive eye exam. So I find it confusing that optometrists, who do not have the ability to test for dyslexia, which is very much like Irlen's in that it's centred in the neural imaging part of the brain, think that they're the experts on Irlen's, or they consider themselves the experts on scotopic sensitivity syndrome.

You and I talked about this, and we talked about the research that you also mentioned in your presentation, and I would say that these were the same comments made 20 or 30 years ago about posttraumatic stress disorder, when people, especially soldiers, complained of headaches, flashbacks, and extreme anxiety. Even though the research was inconclusive at that time, it was a real disorder and had serious consequences. Too late for some people the scientific and medical community finally recognized that PTSD was real and needed treatment. Over 30 years ago chiropractic care and acupuncture . . .

The Chair: Mrs. Jablonski, I know we're getting to a question where at least we're going to give our presenters an opportunity to respond. We have time. We can kind of break it down into bite size. Maybe I'll just ask you to . . .

Mrs. Jablonski: Get right to the question.

The Chair: Yeah. If you would.

Mrs. Jablonski: Okay. I'll get right to the question. Being that 30 years ago chiropractors and acupuncture and other alternative care therapies were discounted as well, I think that Irlen syndrome or the testing for Irlen is in that same category. I have two questions.

I want to know just hypothetically: if it should be recommended to the committee that Bill 204 include a recommendation that anyone showing visual distress symptoms should first have a complete and comprehensive eye exam, would you find that objectionable? That's number one.

Number two we discussed. After all complete and comprehensive eye exams have been done and tests have been completed very thoroughly, as Dr. Penny outlined for us – and thank you very much for that. After all that has been done and you still have not found the solution to the problem, and knowing that screening for Irlen's or visual stress is noninvasive and nonpharmaceutical, and knowing that the cost is not astronomical as you have testified at this meeting – these glasses cost me $600. I think that's outrageous. I think that's astronomical. I have no choice but to have these glasses. I went to every single – you can bet – eye care place in Edmonton and Calgary, and that was the best price I could get. So Irlen glasses are comparable in price.

The question is: after you've done everything you can possibly do, after you've tested for everything you can possibly test, if you still haven't found the solution or the piece of the puzzle, why would you think that recommending Irlen's should not be part of what you say to the parents or the guardians?

Dr. Hensel: Since you phrase it that way, I think I'll answer question 1. I'll let Dr. Penny answer question 2 about the glasses. The issue of adding an eye exam to the bill does not attack the problem, does not solve the issue. It is not a question of saying: let's make eye exams mandatory. That will not do it. The question is: should we have this mandatory recommendation for kids to be sent to an Irlen screener? That's where the problem is. No matter what you do ahead of that, if that's still in the bill, that would be totally unacceptable to our college because the facts are not there; the research isn't there.

Just before I let Dr. Penny answer, you mentioned the name of one optometrist in our province. Just to let you know, .3 per cent of optometrists in Alberta do support Irlen screening and testing; 99.7 per cent do not because they read the scientific literature. The person that you named is in that .3 per cent. Every health care organization has their fringe elements. I have nothing else to say on that.

Mrs. Jablonski: Okay. You read the bill wrong, too. It's not mandatory in the bill.

Dr. Hensel: The referral would be mandatory is the way I read it.

Mrs. Jablonski: And there's a big difference.

Dr. Penny: There are many other areas that, actually, we've tried to touch on initially for reading difficulties that influence reading. It was not our intent to say that the children here present today or that any of the ones that you're dealing with have an unloving family environment. I'm sure they do, but there are a number that don't. The learning disabled have a lot of difficulties in life, and they have reading difficulties. The first step is actually a reading assessment by the reading specialists within the schools. A lot of these children have not had that.

The second step is a psychoeducational assessment by the school psychologist. Unfortunately, due to funding issues the schools have to wait until they're two years behind before they can actually make the referral. The referral takes another year. Yes, this is a problem, but this is something that allows for just normal development of children. Sometimes they'll catch up, but quite often they don't. As well, the school psychologist will also recommend all sorts of different types of recommendations for the classroom with the teacher, whether they need special education, whether they need individual programming. But Irlen lenses are not high on the list.

1:30

You say that they are not being looked at. They were looked at 30 years ago. I was there. When the learning centre brought people in from the Irlen group and they presented – and they looked at them very carefully, and they assessed, and they evaluated – they found that they were not useful. I'm sorry. But that's what happened 30 years ago.

There have been upcroppings over the decades where little pockets of Irlen syndrome people have come forward. This is another little bubble that will go away, just as the others have, because it's not something that actually works. There are a lot of other factors coming into place. I appreciate . . .

Mrs. Jablonski: Dr. Penny, you are so wrong. You are so wrong.

Dr Penny: It is not based on science. I'm sorry.

Mrs. Jablonski: Those are flawed studies.

The Chair: Okay. We have some other questions and about eight minutes left for this section. We're going to go to Mrs. Towle, followed by Mrs. Leskiw.

Mrs. Towle: I want to say thank you very much for coming here today. I know that when you're faced in this arena, it can be a little bit more difficult, so I appreciate your time and expertise and your allowing us to have the opportunity to question you.

Here's the dilemma that I have. I have a nephew who's in grade 9. My nephew is from a good family. His mom is a dedicated mom. My sister-in-law reads to him every night. He can read. He's from a good, average Albertan rural family, a very good student. He had these situations where he saw the letters dance around on the page, that sort of thing. In around about the end of grade 7, early grade 8 – he got his eye exams every two years; his mom is dedicated to that – they identified that he had no vision issues at all, but he still was having difficulty reading. He was excelling in all other areas of school but having difficulty reading. He did go in for Irlen testing. He was successful. He got the blue-tinted lenses, and the child is now an honour student in all levels of school.

Here's my dilemma. Is it not possible or in the realm of possibility that a person can go through all that you're saying, that they can go through the eye exams – perhaps we need to be a little bit more open minded and see if there is a possibility that this is working for some kids. Along with that, I understand what you're saying about that the science is not there yet, and I understand where your organization comes from, and I'm open to hearing more – please don't take this the wrong way – but I just sort of have a real-life situation in my family, and I need to understand this. One has to wonder. Is there any possibility from the optometrists' point of view that you can go through all of the eye exams, have good vision, have the reading assessments done in the school as my nephew did, and then if you still come out and you can't read and the Irlen lenses help, is that not worth consideration by your association? If we could eliminate half of what you're saying needs to happen with a simple set of lenses, is that not even worth considering?

Dr. Penny: The problem is, as we mentioned, that it's such a small percentage of people that fall into the category that are actually helped. One, it shouldn't be legislated. There are a lot of reasons why it should not be legislated. Two, if he has gone through that, then also look at alternative therapies, which is what he did. We're not saying that for a certain small percentage, yes, that maybe it does work. But it should not be in legislation. That is the freedom of choice of the individual, when they reach that point, to seek alternative therapies.

Mrs. Towle: Just so I understand what I'm hearing, your opposition is the fact that it's legislated.

Dr. Penny: Correct. For many, many reasons which we went over.

Mrs. Towle: Okay. I just want to understand because your previous statements made it sound like you were against Irlen testing completely.

Dr. Penny: Personally I am.

Mrs. Towle: Okay. But you're not here personally, right? You're here as the optometrists group?

Dr. Penny: I'm not here personally. That's correct.

Mrs. Towle: So as I understand your previous statements – I just want to make sure I'm clear so that I can talk to my constituents when we go home. Your previous statements made it very clear that you were opposed to Irlen testing, that you didn't believe in the science, that it wasn't scientific enough. Now when I'm asking you this question, it sounds like you're actually saying that you're just opposed to the legislation.

Dr. Penny: That's what we said.

The Chair: Okay. I think we'll move on to our next question, then, at this point. Mrs. Leskiw, followed by Ms Notley if there's time. If we can keep our comments brief, we'll try to get them both in.

Mrs. Leskiw: Okay. Before I became a politician, I was a teacher for 37 years. In those 37 years I saw things come and go, from whole language to phonics to whatever. Every time a new idea came out, they would say: "No, you can't use that. No, we have to go now to new because the old is no longer any good." As a teacher I always said that, no, if there was one student in my classroom that could benefit from whatever was out there, then as a teacher I was going to use it.

What I can't understand is that if this Irlen testing can help one student in every classroom out there, why in the heck would you not recommend it? The legislation says only that teachers recommend testing to parents. If I was still in the classroom and I had a student that after trying everything had failed, I would be failing as a teacher to not recommend whatever was out there to help that student. If Irlen's can help a student in every classroom in Alberta, then not only as politicians but as educators it would be up to us to recommend it. My question to you is that if it's going to help, if the optometrists can't help child A, B, or C and this can, why would you stop it from happening?

Dr. Hensel: Mrs. Jablonski and I had a conversation about that exact same topic. I agree with you. If there is something that will help a child achieve better in school, become a better learner, read better, I am all for it. I have nothing against that whatsoever, and I hope there is nothing we said today that you took to be against that. We are all for our children, and there are people behind us sitting with their Irlen lenses that attest to the fact that they have been helped by it. But you have to realize that there are hundreds and hundreds of thousands that are helped by other things.

Mrs. Leskiw: Absolutely.

Dr. Hensel: When you look at that and say that for every child there will have to be mandated referrals – it's not that they have to go but that they have to have the referral – the parents will do anything the teacher says. If the teacher says, "Let's go do this," the parents will say, "No problem; I'm all for it." This is where the problem is. You are mandating that referral for all those children who may or may not have something called Irlen. I agree with you to do everything for the children, but that doesn't mean putting this bill through. Putting this bill through is wrong.

The Chair: All right. Thank you.

Ms Notley, you've got about a minute and 17 seconds. If you would like to go ahead, please do.

Ms Notley: Okay. I'll be as quick as I can. My question is to you, and you may or may not be able to give us this information, but if you can with your experience. You know, let's say that you've got kids that come through the door with a series of symptoms that have been listed in your document. Roughly speaking, say that you go through the first round of testing, the straight-up optometrist testing, that you do that sort of comprehensive testing and there's no clear explanation. In your experience what's the next subset of tests that you would normally go to based on your understanding of what is the common explanation for those problems, and how do those subsets ultimately relate to where you get to Irlen's as an explanation? My understanding is that there are lot of other sort of learning disability types of things that you would be looking at at that point that may well be much more commonly diagnosed and that you'd be going to before you got to Irlen's. I'm just wondering if you can sort of speak to that.

Dr. Penny: That's actually quite to the point. Yes, I actually see a lot of referrals from other ophthalmologists and optometrists as well as school psychologists and teachers for kids that have learning difficulties. [A timer sounded]

The Chair: Go ahead. Finish up.

Dr. Penny: Thank you.

Ms Notley: Can you maybe provide us that? Would that be okay, to provide us that in writing?

Dr. Penny: Sure.

Ms Notley: I don't think they're going to let you talk any longer.

Dr. Penny: Are you going to let me finish? No? Maybe?

The Chair: A minute is fine.

Dr. Penny: A minute? Thank you. I'll be fast.

I would look at doing a basic exam, but we do further in-depth testing in the areas of tracking, focusing, and eye co-ordination. If the signs and symptoms indicated it, we would also do visual-perceptual testing, which looks at the areas of visual memory, eye-hand co-ordination, letter reversals, all the visual-spatial types of areas and visual-perceptual areas as well.

1:40

I do a lot of referrals to other agencies as well. I use occupational therapists, physiotherapists, speech-language pathologists. I use reading specialists, and I use educational psychologists, sometimes pediatricians if there are indications of health issues as well. So it is a very comprehensive assessment. I have never actually utilized Irlen lenses because I have not supported that. I believe it's a combination of both placebo and Hawthorne effects.

Ms Notley: I have another question that I'll maybe ask you later to see if you can send us some information.

Dr. Penny: Okay. If you'd like to send it to Gord, he'll forward it to me. Thank you.

Dr. Hensel: Just to the college.

The Chair: Okay. Thank you.

Well, Dr. Hensel and Dr. Penny, thank you very much for your submissions. You're free to go or to stay and, of course, watch the rest of the presenters, depending on how your time is.

Dr. Penny: Thank you.

Dr. Hensel: Thank you very much.

The Chair: Mrs. Fritz, a short clarification on the bill for Mr. Reynolds.

Mrs. Fritz: Thank you, Mr. Chair. I just have a request for the Law Clerk for a clarification of the bill under 3(1). My understanding from the presenters is that they feel the intent of the bill is that it must be mandated by teachers to the parents or guardian that they must have their child tested for Irlen syndrome. My understanding is the bill says that 3(1) is really a referral, you know, in the sense of not that it be mandated but that it's just making the recommendation to the parents or guardian that they be tested. They're letting them know. It doesn't mandate that you must take your child to be tested.

Mr. Reynolds: Mr. Chair?

The Chair: If you like, or do you want some time to look at it and respond later? It's up to you.

Mr. Reynolds: I can respond quickly to what you say about 3(1) in my interpretation, taking into account that I'm not a judge deciding this. I would say that, yes, 3(1) is "must," a mandatory recommendation to the parents or guardian that he or she be tested for Irlen syndrome. However, 3(2) then says:

> Upon receiving written consent from the parent or guardian of a student,

which I assume would have been in response to the note under 3(1),

> that student must . . .

That's mandatory once again.

> . . . be tested by a screener who is made available by a board under section 2.

So, yes, they would get the permission of the parents, but once they have the consent, the student must be tested. In my estimation it would appear to place a duty on a board to ensure that there were screeners made available.

Thank you.

The Chair: Okay. Thank you for that clarification.

I would like to invite Ms Nola Stigings and Ms Judy Pool from the Canadian Association of Irlen Professionals to the table.

Again, just a reminder that the microphones are operated by *Hansard* staff, so you don't have to do anything with those. You know, of course, that the meeting is open to the public and recorded by *Hansard*.

I have introduced you, but I'm going to ask you to just introduce yourselves for the record to make sure I've done that correctly. Then go ahead and start whenever you're ready. There are 15 minutes for the presentation and 15 minutes for questions. Please go ahead.

Canadian Association of Irlen Professionals

Ms Stigings: Thank you. Good afternoon, members of the committee. My name is Nola Stigings. I'm an Irlen clinic director established in Innisfail, Alberta. I'm also president of the Canadian Association of Irlen Professionals. This association was established to facilitate the identification, treatment, and dissemination of information about Irlen syndrome and to encourage excellence in practice by the members.

Can everybody hear me? Would you like me to repeat that?

The Chair: I think we got the first part of that.

Ms Stigings: Okay. Today we're here to talk about Irlen syndrome. It's the time of year in Alberta when the sun is low in the sky. The other day I was driving west, and the sun was in my eyes. It was hard to see and even more difficult to concentrate. I nearly had to stop. It was so bright that I didn't feel like I was driving safely. I know you have experienced this.

Now I want you to think about what it would be like to feel this intense degree of brightness all of the time. Imagine what it must be like to experience that feeling every time you open a book to read or look at a whiteboard.

As an Irlen screener and diagnostician I have heard many heart-wrenching stories from clients. I've seen the relief they experience when the correct coloured overlays are placed on the white page. I've heard them read and have seen the tears of joy time and time again. When I heard Mrs. Jablonski was introducing this private member's bill, I was filled with anticipation. What a difference this could make in the lives of so many struggling students.

Over the last few weeks your committee has been presented with a lot of information about Irlen syndrome. You've heard that it's not an optical problem but a neurological problem. I want to make it clear that as part of the Irlen protocol a recent optical exam within the past six months is recommended before screening for Irlen syndrome is done. For some individuals the visual eye exam recommended by the Irlen screener is the first they have had in several years, if ever. Correcting for Irlen syndrome will not correct existing optical problems. These problems need to be addressed by the optometrist. As Irlen professionals we fully support all the work done by optometrists because we understand the role optimal vision has to do with learning.

Submission 038 from Dr. Susan Leat, professor at the School of Optometry and Vision Science in Waterloo, suggested that after an assessment and correction of visual disorders, if symptoms persist, an assessment for coloured filters or lenses should be considered. Optometrists and Irlen professionals working co-operatively can provide optimal treatment for children with both vision and Irlen syndrome difficulties. This practice is currently in place with many optometrists.

You have heard that researchers disagree on the underlying physiological mechanism for Irlen syndrome. I'd like to point out that this is also consistent with the status of many well-known educational difficulties and medical disorders. Among these are autism, dyslexia, and ADHD. At this time no one is advocating for a delay of intervention for any of these difficulties until their precise causes are determined. The lack of an identifiable cause should have no bearing on the fact that there exists a significant body of research and clinical practice that supports the Irlen method as an effective technique designed to treat this disorder.

You have heard concerns about costs and the extra workload for teachers. We are not asking for money to do the testing or for training for teachers to test in the schools. Parents already pay for the testing, and there are a number of sources for funding available in our province for those who can't afford it.

CAIP would like to see a list of certified Irlen screeners available for each school board in Alberta. We already have a strong structure of independent Irlen professionals in Alberta. There are three certified Irlen diagnosticians, more than any other province. In addition, in Alberta there are already 108 trained, certified Irlen screeners listed with the Irlen Institute. Screener training workshops are available several times a year in order to increase this number. In most schools, colleges, and universities in Alberta Irlen overlays and the use of coloured paper for students are already accepted accommodations.

Special ed students cost dollars. Projects such as the Pioneer Valley project show how 50 per cent of special ed children return to regular education status simply with the use of Irlen coloured overlays, leading to an estimated savings of nearly $7,000 per year per student. The use of overlays would be providing a support for these students that they need so they can be more included in the system and not feel like they are being left behind.

We are not asking for exclusive consideration. We are simply asking to be included in the list of considered interventions for struggling students. As part of the list of educational specialists we, too, could have a part in the continuum of support for students, helping to make it possible for these students to have their needs met. Teachers, doctors, psychologists, optometrists, and Irlen professionals have common concerns: the well-being of our clients and the desire to help them be better able to function in life. We have this opportunity to help improve the learning conditions for Alberta students. Don't let this opportunity pass us by. Reading is vital not only to a child's success in school but to a child's confidence and self-esteem.

Thank you.

Ms Pool: Good afternoon, members of the committee. My name is Judy Pool. I'm part owner of Reading & Writing Consultants, which is also Irlen centre Alberta. My company is unusual because we have reading specialists as owners and tutors. As reading specialists we all obtained master's degrees, which included intensive reading assessment and reading remediation courses through the University of Alberta education department. I will explain how certain issues we found with the students we tutored led us to becoming involved in Irlen syndrome testing. In what I'm describing, I'm only talking about the overlays because that's what's in the bill. I'm not talking about going on to the glasses, so just to make that clear.

1:50

I have some description about the research into reading. Becoming an efficient, fluent, engaged reader is a complex process. It includes learning and implementing phonological awareness, phonics knowledge, decoding skills, sight word recognition, vocabulary knowledge, general background knowledge, use of contextual cues, comprehension, fluency, reading speed, and motivation. When we tutor students, we assess the student's ability in each of these areas and plan remediation according to their strengths and weaknesses. For some students that assistance is all they need for their reading to become fluent and efficient.

I have a diagram here. It's from *Overcoming Dyslexia* by Sally Shaywitz. She summarizes how students' reading test scores differ in respect to the average amount of time they spend reading each day, and this graphic really illustrates this concept. I want to explain that the test scores on the graph are measured in percentiles. For those of you not familiar with percentiles, it's a comparison to 100 other people exactly the same age as the person being tested, so same birthdate, everything. If they have one minute of daily reading, that equates to readers being below the 10th percentile. So that means 90 per cent of their age mates will be reading better than them. Five minutes equates to being at the 50th percentile, so that would make them average. Twenty minutes of daily reading equates to the 90th to the 100th percentile. How much a person reads significantly impacts their reading.

The teaching implications for that are that teachers in elementary and junior high school have implemented this information into their teaching programs. Beginning in grade 1 they assign home and classroom reading in addition to their strong focus on reading instruction. Many of them use incentives to motivate students to increase the number of books they read. So teachers are doing a good job.

As a side note, when we're tutoring, we complete a history form for our tutoring students. They have their eyes checked, and they often have had extensive psychoeducational testing, much of the testing that has already been mentioned. We also test them to determine the current reading level and to connect any issues from the history to the ongoing tutoring. As we know how important copious reading is for a student to become an excellent reader, we ensure that each student reads for about 20 minutes in our sessions in addition to reading at home. In order to increase their motivation to read, we also keep a reading log and award prizes. We try to significantly increase the number of words they read to improve their reading and help them catch up.

For some just that intervention works really well. Others, even though they are at their appropriate reading level – in other words, it's a reading level that's independent for them, not necessarily their grade level – some of them are unable to maintain efficient reading for more than five to 10 minutes. We try to extend their reading with each tutoring session. They do fine for five minutes. Then they start making mistakes more frequently and are unable to read words that they had easily read on the previous page. When their reading deteriorates, forcing them to keep on reading is counterproductive as no meaning-making is happening. Less visually stressful tasks are then used in order to complete the session.

The inability of our students to do extended, efficient reading was one area for which we didn't find a solution through our course work, research articles, or textbooks. A possible solution came to light as I read Helen Irlen's *Reading by the Colors* and came across a suggestion to ask the student what is happening on the page. None of my course work had suggested that. When I began checking with my students, I started to get answers that I'd never considered. The students' answers indicated that looking at the page of print caused considerable difficulty for them.

To give you an example of how difficult it was for these students, as Nola has already suggested, you can imagine you're driving down a road directly into the setting sun. You have no sunglasses and no sun visor. You can make yourself look at the road, but you're not seeing anything very clearly. Would you do this willingly and enjoy it while you're doing it? You don't while you're driving, so why would you while you're reading? For some individuals with Irlen syndrome that is what reading black print on a bright white page is like. They can't imagine why anyone enjoys reading when they find it such hard work. One comment by a student identified with Irlen syndrome was: when I try to read, I feel like I'm in a crowded room and everyone in the room hates me.

So we then trained as Irlen screeners. I was skeptical but felt it was worth trying. To my surprise, we found that coloured overlays significantly improved the page for a number of our students. Contrary to all the naysayers, it was easy to determine whether the overlays were working. Many students who previously could only read effectively for five minutes could now read for 15 to 20 minutes. It's a simple measurement.

Reading for longer meant increasing their reading mileage, meant each time they read a sight word the path to that word in the brain became stronger, meant that the student became more capable as a reader, and meant that they became more fluent and, therefore, had more access to understanding and remembering what they were reading. Using the overlay was a tool to reverse the negative cycle of their previous reading experiences. Using the overlay, it was possible for them to integrate and use phonological processes efficiently, to read in context for longer, to learn their sight words faster, to practise their decoding skills more effectively, and to progress more quickly in their acquisition of reading knowledge and skills.

My response to the research. Do I think research is important? Yes. I keep up with new research on Irlen syndrome and in the field of reading. I evaluate new research in terms of whether it is helpful and makes sense to me as a reading specialist. Do I think research replaces common sense? No. If a student can read longer with an overlay, my common sense plus the research on reading mileage means that overlays are an important tool to make our students more competent readers. Delaying help for even one student is not acceptable to me.

One of the criticisms leveled at Irlen syndrome testing is that positive changes could be a result of the placebo effect. If you think something is going to help, that belief results in improvement. I would like you to take another careful look at the testimonials that have been submitted. Pay attention to the differences the person is describing. Ask yourself if you think the magnitude of those differences could possibly have happened because that individual believed the overlay or the Irlen spectral filters would fix all their issues. If you still believe it's a placebo effect, then why wouldn't we take advantage of this placebo effect to help students?

I also want to mention that currently we see many students referred for Irlen screenings and lens assessments from the University of Alberta, Grant MacEwan, NAIT, Norquest College, and other postsecondary institutions. These students are struggling with the vastly increased reading requirements at the postsecondary level. This year we have assessed or are in the process of assessing 25 postsecondary students for Irlen syndrome. All of them would rather have had this difficulty identified when they were in the regular school system.

Thank you.

The Chair: All right. Thank you very much, Ms Pool.

We'll move on to questions. First of all we have Mrs. Jablonski.

Mrs. Jablonski: Thank you very much, Mr. Chair. He's not favouring me. I get my hand up first. That's why I get to go first.

I want to thank you two for being here as well. You are two of the three Irlen diagnosticians that we have here in Alberta, so I really appreciate that you're here. I find it very confusing that one reading specialist, Dr. Penny, says one thing and then another reading specialist, Judy Pool, says another. So if it's confusing for me – and I've read a lot of research over the last year – it must be confusing for many other people. But you know what? It's not confusing to the kids that wear the lenses and who start to succeed in school and start to feel better about themselves. And you know what? That's all I care about.

My question to you. You said you believe in research. I have documentation here up the yingyang that tells me that a lot of the old research was flawed, and I have doctors criticizing other doctors because of the flaws, but here's a piece of research that we've just recently had with this committee. The research comes from James Irvine. This is interesting. He's the senior program manager for production on the Sidewinder guided missile, a missile that supplies 60 per cent of the free world's air-to-air combat capability.

He was involved in testing in the military, and his conclusion and other doctors' – and I'll tell you the doctors who conclude along with him – is that the Irlen effect is real. I know I have to make this fast. He says that Dr. Jeffrey Lewine of the University of Utah ran tests using brain scanning technology – I have a picture of brain scans over there – and was able to identify that Irlen syndrome was real and it affects about 26 per cent of the human population on Earth. Other doctors that agree with Dr. Jeffrey Lewine are Dr. Arnold Wilkins of Great Britain, Susann Krouse, Dr. Gregory Robinson of Australia, and, of course, the gentleman who wrote the letter. He says the problem is that if it is as widespread as the results indicate, why is it not recognized and more widely treated?

My question is: are you aware of this piece of research?

2:00

Ms Pool: I'm familiar with all of those, yes.

Mrs. Jablonski: Okay. Thank you very much.

The Chair: That was the question?

Mrs. Jablonski: That was the question.

The Chair: All right. Mrs. Towle.

Mrs. Towle: Thank you very much again for coming here today. I actually have three different parts to the question I have. The first one is: why does the screening have to be so expensive? As I understand, it's around 250 bucks. Why does it have to be that cost?

Ms Pool: The screening itself takes two hours to do. Plus, we have our screeners do a written report that takes about two hours to do. So you're talking about four hours of involvement. The reason the screening takes so long is because everybody thinks that what they see is the same as what everybody else sees. When we're doing a screening, as well as determining that the person actually has Irlen syndrome, at the same time we're educating the parent and the child or the person on exactly what this means and exactly what's happening and how it's different from other people and what needs to be done about it, like what they can do in their environment to do it.

Mrs. Towle: Along with that and keeping in mind what the optometrist said – actually, I take his point quite seriously as a parent – I'm curious to know why the lenses are restricted. If we're doing this for the betterment of children, and that's really what you want, why is the actual colour-coding of the lenses restricted? Why would you not work with optometrists to possibly have this be accessible to more if it's truly revolutionary?

Ms Pool: It's not as simple as just giving a colour profile. When I do the lens assessments, some people have eight different colours put together to get the exact right colour for them. If you have one colour a little bit more saturated than it should be, then people get headaches or it doesn't work or it feels too dark and they just can't wear them. So the tinting has to be very precise. I'm not saying that somebody here couldn't be trained to do it, but to get it exactly right, you need to have a lab that's very familiar with it and knows how to do it. I think Helen should probably speak to that more when she's up. She'll know more about that.

Mrs. Towle: The third one is: how many children right now are actually wearing Irlen lenses in Alberta? Do you know?

Ms Stigings: Children?

Mrs. Towle: Or people. Whoever. Sorry.

Ms Pool: Well, I've probably tested close to 2,000.

Ms Stigings: And another 500 or 600 for myself.

Ms Pool: Both Beverley Butt from Saskatchewan and Adel have come in and tested other people. But it's the tip of the iceberg. It's just a drop in the bucket of what needs to be done.

Mrs. Towle: Thank you.

The Chair: All right. Thank you.

We've got Mr. Goudreau, followed by Ms Notley.

Mr. Goudreau: Well, thank you for your presentation. As Mrs. Jablonski indicated, this is very, very confusing, and it's going to be a daunting task for this committee to eventually make a decision as to what and how fast this can proceed, if at all. I guess I have two questions. How do you become a certified screener, and who decides that you're a certified screener? Then the other question is: of all the people that come to you, what percentage of them are diagnosed as requiring Irlen's? Are you going through thousands and thousands of people to find four, for instance, or are the numbers much higher?

Ms Stigings: Okay. The first question is simple to address. The Irlen screeners are trained by Irlen diagnosticians. They have an application process. They have to be educated to have a degree in education, psychology, sociology, occupational therapy. We have a variety of different professionals who apply to train to be Irlen screeners. The screeners have a one-weekend training course, very intensive, and they pay for it themselves. Judy and I are both trained to teach this course.

As far as how many people that we see for screening, I'm not sure of the question. Was it how many that we screen have Irlen syndrome?

Mr. Goudreau: That's right. Say out of a hundred people that you look at, how many would end up with . . .

Ms Stigings: Okay. Well, the process starts with a self-test, and when they fill in the self-test, if they answer yes to X number of questions, then they're concerned: oh, this may be our solution. When they come to us, we test them. The series of tasks we take them through tells us whether they're slight, moderate, or severe symptoms. If they're slight symptoms, they may or may not benefit from an Irlen overlay. If they're moderate or severe and show benefit, then the recommendation is made to consider the lenses. That's it.

Ms Pool: I'm going to answer that question a little bit more. Because of the self-test that's sent out, if somebody comes back with a self-test and has only three or four yeses on it, then we would say: we're not going to bother testing you. I don't want to test somebody that doesn't have Irlen syndrome. I'd say that of the people that actually get to us, probably about 98 per cent or maybe 95 per cent, somewhere around there, would come out in the moderate to severe range.

Mr. Goudreau: Thank you.

The Chair: Thank you. All right.

Mr. Khan, did I hear you join the meeting on a call? I'm sure I heard Steve Khan come on the call.

Ms Notley, followed by Mr. Wilson, please.

Ms Notley: Well, yeah, I guess my question was right along the same line as Mr. Goudreau's, actually, exactly the same question, but now I sort of want to follow up a bit. It raises a flag for me, I have to say. I mean, the rationale that we're being asked to consider is the notion of recommending this testing to see if this is the issue, but an issue first appeared to me when you said: oh, part of the reason it takes so long is because I spend a lot of time talking to the family and explaining Irlen's to the family and stuff. When you were talking about it, I thought: well, are we kind of presupposing that diagnosis at that point? Then you're saying that, actually, for pretty much 98 per cent of the folks that you test, you will make recommendations around Irlen's. So, really, the test is the self-screening form that they're filling out. If we're talking about tests in the way people typically use the word "test," what you're really describing in many respects is treatment already. You're actually going into treatment. You're not testing; you're kind of already there. You're already working with people where you've decided that that's the thing.

My question is: are we really talking about just asking school boards to give people the self-tests that they give to themselves? Is that what we're asking for, or is there a difference? The second follow-up question was – Mr. Goudreau also asked about the training, and Mrs. Towle also asked about why could we not share it more with the optometrists. You talked about the need for the specialty and the refinement, and I do appreciate that. I know you personally have a great reputation. I've heard many wonderful things about the work that you do.

Ms Pool: Thank you.

Ms Notley: So I know it's there, but then I hear that you've got basically a weekend certification process, and I become concerned about that because I think there are a lot of optometrists out there that do weekend professional training all the time, and I'm not just talking about optometrists, because they're not necessarily the people that should be doing this anyway.

The Chair: Ms Notley, can we just skip to that second question, please?

Ms Notley: Sorry. I go back again. My question is: why is it not possible to expand greatly the number of people who can test for Irlen's if, in fact, it's not just about a copyright kind of thing?

Ms Pool: To do the screening?

Ms Notley: Yes.

Ms Pool: I mean, it can be, but right now it's difficult for people to become – not difficult to become screeners. But they can't go into the schools and test if the schools are against it. You know, it's not valuable for them to take the screener training if they don't have a client base. It's like a catch-22 situation. Either the schools accept that Irlen's is a possibility and make referrals, and then there will be people who can do the testing, or the pool of Irlen screeners is going to remain small.

To go back to your chicken and egg thing, there's a series of tasks that people do as they're going though the screening. The education kind of goes along with it, but, you know, if we have people who go through and they look at the task and they say, "What do you mean by 'Is anything happening there?'" of course not. We don't do that part of it, the education part of it, because they turn out not to have it.

Ms Notley: That's about two per cent of the folks that you'll see, though, right?

Ms Pool: Well, or maybe five. It's not very many. Yeah. We've already done a lot of pretalking to them. I often spend an hour on the phone talking to somebody before they come.

Ms Notley: Okay. Thanks.

2:10

The Chair: Thank you.
Mr. Wilson.

Mr. Khan: Mr. Chair.

The Chair: Go ahead. You've got about two and a half minutes. Please go ahead.

Mr. Khan: Mr. Chair, if I can.

The Chair: Yes, go.

Mr. Khan: Mr. Chair, this is Steve Khan. I'm sorry; it took me a little while to unmute my phone. I've been in the call for about the past 25 minutes, and I'm en route, so I hope to join you shortly.

The Chair: That's good, Steve. We'll see you when you get here.

Mr. Khan: Okay. Thank you, Mr. Chair.

The Chair: You bet.
Mr. Wilson, you had a question. Are you on the call still?

Mr. Wilson: Yes, I am. Thank you, Mr. Chair. I appreciate the opportunity to address our guests here.

The Chair: All right. Sorry about that. We'll add a little bit of time on for you there. Go ahead, please.

Mr. Wilson: I'll make it very quick. I apologize, ladies, if this sounds overly cynical, but I'm just curious how much your clinic stands to make in the event this bill passes.

Ms Pool: Mine is not going to make very much more because we're almost running at capacity now.

Ms Stigings: Mine might be busier. I may be training more Irlen screeners. My own clinic, personally, likely wouldn't change a lot because I myself tend to not do Irlen screenings. I refer them out to the screeners I've trained, and I focus on the lenses.

The Chair: Okay. That was your only question, Mr. Wilson?

Mr. Wilson: Yes. Thank you.

The Chair: All right. Very good. Then that concludes the list of members with questions.

Thank you both for your presentations here this afternoon. You're free to go or, again, stay if you like, as long as you're able, to watch the rest of the presentations. Thank you, again.

All right. We have our presenters here from the Alberta Medical Association. Can we have you join us at the table, please.

Just checking on whether the presenters have any information they would like to have up on the screen.

Dr. Sharon: While we get the USB stick to you guys, do you mind if I just introduce the four of us?

The Chair: That would be just great. If you're all ready, please introduce yourselves.

Dr. Sharon: Thank you very much for inviting us as the representatives of the Alberta Medical Association to talk about Bill 204. I'd just like to introduce the speakers. To my left is Dr. James Lewis, who is a pediatric ophthalmologist and associate clinical professor at the department of ophthalmology here at the U of A. To my right is Dr. Ian MacDonald, professor and chair of the department of ophthalmology at the U of A. At the far right is Dr. Lyle Mittelsteadt, who is a senior medical adviser for professional affairs at the AMA. My name is Raphael Sharon. I'm a pediatrician here and the current president of the section of pediatrics of the AMA.

The Chair: Thank you very much. Were you gentlemen all in the room when we did the introductions of the members at the beginning of the meeting?

Dr. Sharon: No.

The Chair: In that case we'll go around the table and very quickly do that, starting on our right with Mr. Reynolds.

Mr. Reynolds: Oh, I'm actually not a member, but I'm the Law Clerk. My name is Rob Reynolds. Thank you.

Ms Zhang: Nancy Zhang, legislative research officer.

Ms Leonard: Sarah Leonard, legal research officer.

Ms Robert: Good afternoon. Nancy Robert, research officer.

Ms Notley: Rachel Notley, MLA, Edmonton-Strathcona.

Mr. Goudreau: Hector Goudreau, MLA, Dunvegan-Central Peace-Notley.

Mrs. Towle: Kerry Towle, MLA, Innisfail-Sylvan Lake.

Mrs. Jablonski: Good afternoon, welcome, and thank you very much for being here this afternoon. I know how busy you must be. Mary Anne Jablonski, MLA, Red Deer-North.

Ms Cusanelli: Good afternoon. Christine Cusanelli, the MLA for Calgary-Currie.

Dr. Massolin: Good afternoon. Philip Massolin, manager of research services.

Mr. Tyrell: Good afternoon. Chris Tyrell, committee operations.

The Chair: Dave Quest, MLA for Strathcona-Sherwood Park.

Ms Rempel: Jody Rempel, committee clerk.

The Chair: All right. Just a reminder that the microphones are operated by *Hansard*. There's nothing that you have to do there. The meeting is, of course, open to the public and recorded by *Hansard* and streamed online.

Please go ahead.

Dr. Swann: It's David Swann in Calgary.

The Chair: Oh. I'm sorry, David. I'm sorry. I forgot about our folks on the phone.

Dr. Swann: Thanks.

The Chair: Who else is on the phone?

Mr. Wilson: Jeff Wilson, MLA, Calgary-Shaw.

The Chair: Thanks, Jeff.

Mr. Pedersen: Blake Pedersen, MLA, Medicine Hat.

Mr. Khan: Stephen Khan, MLA, St. Albert.

The Chair: All right. My apologies to those on the phone again.

Please carry on with your presentation, 15 minutes or so, and then 15 minutes for questions and answers.

Alberta Medical Association

Dr. Sharon: Okay. Thank you very much. It's a brief presentation that we jointly will make – and hopefully at the end we'll get to the conclusion that's up there on the board – that will demonstrate that there's insufficient evidence to support any screening or intervention for this unproven and controversial disorder, and disorder in quotation marks.

About 1 in 16 kids in Canada has a learning disability, so about 6 per cent, and the majority of these by far have dyslexia, which is primarily a reading disorder and results from a processing abnormality for the written word by the brain. This 80 per cent are the ones that account for the majority of the learning disabilities.

Dr. MacDonald: Visual processing is a higher cortical function. It's decoding and interpreting the retinal images, and that occurs in the brain after the visual signals have been transmitted from the eyes. Reading involves adequate vision and neurologic activity and the ability to identify what's being seen. Research has shown that reading disabilities are really not caused by altered visual function.

Because learning disability is difficult for the public to understand and for educators to treat, learning disabilities have spawned a wide variety of controversial and scientifically unsupported alternative treatments, including vision therapy, eye muscle exercises, and coloured filters. Tinted lenses and filters have been suggested to treat visual perceptual dysfunctions caused by sensitivities to particular wavelengths of light but not to treat language-based dyslexia. Scrutiny of published study results that advocate the use of these therapies has shown serious flaws in their methods and inconsistencies in their results. On this slide there's a delightful girl from northern Alberta who suffers from a genetic disorder that creates significant photosensitivity, and she's benefited significantly from tinted lenses and doesn't have any learning disability.

Dr. Lewis: The American Academy of Pediatrics, the American Academy of Ophthalmology, the American Association for Pediatric Ophthalmology and Strabismus as well as the American Association of Certified Orthoptists made a number of recommendations, most recently updated in 2009, and the most relevant of these are listed here. One, there should be a strong focus within the schools on early detection of learning disorders and early referral for potential intervention. Secondly, pediatricians and family doctors should perform periodic eye and vision screening. Thirdly, if there's any doubt that vision might play a role in a child's learning disability, a referral should be made to a pediatric ophthalmologist or, we would add parenthetically, to an optometrist with an interest in children. Fourthly, diagnostic and treatment approaches to dyslexia that lack scientific evidence of efficacy such as behavioural vision therapy, eye muscle exercises, and coloured filters and lenses are not endorsed or recommended by these various academies.

Dr. Sharon: When it comes to the focus on the role of education and learning disabilities, early detection, evaluation, and treatment are important. The recommendations from the report are that elementary school teachers should look at difficulties more particularly with alphabet recognition in kindergarten, difficulties with phonemic awareness, and rapid naming. That's around kindergarten and grade 1.

Dr. Mittelsteadt: Based on the scientific evidence, then, we cannot support Bill 204, and the AMA urges that the government withdraw this bill, which would force school boards to test for a diagnosis which has not been proven to exist, with recommendations for a treatment that has not been found to be effective.

We believe that current resources should support screening for learning disabilities and screening for vision problems where there is proven treatment and proven efficacy. We also feel that encompassing within legislation Irlen syndrome at a time when there is not sufficient evidence to either recognize that it is a definitive diagnosis or recognize that the treatment for this syndrome is efficacious would give credence to a syndrome through legislation when the evidence is not there to support either its existence as an entity or the efficacy of its treatment. Also, at a time when school boards are very much strapped for resources, we feel that this is not the point in time when school boards should be putting resources into an unproven area.

2:20

The Chair: All right. Thank you, gentlemen.

Well, that leaves lots of time for questions. Mrs. Jablonski, followed by Mrs. Towle. Mrs. Jablonski, if I can just get you to kind of condense down more to the question, that would be great. Thank you. Please go ahead.

Mrs. Jablonski: Thank you, Mr. Chair. I'll try to make my preamble as concise as possible.

Once again, thank you, all, very much for being here. I find it very comforting to have knowledgeable gentlemen who can all see well and maybe don't have anybody in their family who have Irlen syndrome advising us on what is right and what is wrong. You submitted a document to this committee, and the document bases a lot of what it says on a study done by Ritchie et al. from 2011 in the *Journal of Pediatrics* titled Irlen Colored Overlays Do Not Alleviate Reading Difficulties. I find it further confusing that he would say that, and I just wonder if you have seen this study documented by Dr. Kevin Anstrom.

Dr. Kevin Anstrom says that he read the Ritchie et al. *Pediatrics* paper, and while there are many important design features that strengthen the study, he has some very serious concerns about that study. I'll try to be very brief.

> First, the study was not adequately powered even if the authors performed the correct analyses . . . Second, the authors have not clearly identified the reason for giving the "wrong" colored lenses. Unfortunately with their data analysis, the addition of the second "treatment" served to further reduce the power [of the study]. Third, and most embarrassingly, the authors eliminated the best two responses and a third with a strong response. There is absolutely no valid reason to exclude these data points after the fact.

So this is Dr. Kevin Anstrom. I'd like you to look at his study and what he has to say about the study by Ritchie et al. that you based your comments on.

My question to you is: are you aware of Dr. Kevin Anstrom's study, which refutes Dr. Ritchie's study?

Dr. Sharon: I'm not aware of that study. I just wanted to clarify that we didn't base our comments on one study but, rather, based it on the report made by the combined association of the Alberta academy of ophthalmologists, the pediatric ophthalmologists, and the American Academy of Pediatrics, who had a committee of various experts look at several studies. One of their main studies that they pointed out was that study by Ritchie, but it wasn't the only one that was looked at.

Mrs. Jablonski: Thank you. My supplemental question is this. Although I have a great deal of respect for research and studies and that sort of thing and I think that we do need to look at them, I find that research moves at glacial speed, and I would say to you, knowing what we know now, that I, for one, am not willing to sacrifice another generation of children while we wait for the research to be complete and to be deemed conclusive. Research does move at a glacial speed, and I would say to you and ask if you agree with me or not: if we'd moved faster on the research for posttraumatic stress disorder and fibromyalgia, for example, would we have saved a lot of people a lot of grief and would we have saved some lives?

Dr. MacDonald: I don't deny that research takes time. Research is very important. Research takes a lot of time, and it takes experts. It takes participation. We talk about class 1 evidence. That's a randomized, controlled trial where you would take a number of individuals and decide whether the effectiveness of an intervention such as Irlen lenses or tinted lenses would improve function. That takes time, takes energy, takes money, and I don't think that has been done in this case. Forgive me if I'm wrong.

I just wanted to point out that what Dr. Sharon was talking about was the American Academy of Pediatrics, not the Alberta academy of pediatrics.

Dr. Mittelsteadt: Could I make a comment on that, too? I think that there are risks as well in moving too quickly. I think that all of us who work in medicine for any period of time become aware of instances where certain things are touted as dramatic cures. The one that comes to mind for me is Laetrile. Several years ago it was a cure for various types of cancers. It was not recognized: "Why is the medical profession not moving more quickly to embrace this new treatment?" People were travelling down to Mexico to receive Laetrile therapy. Subsequently the evidence was that it did not work, it was not saving any lives, it was costing lives, and it was providing false hope to people.

I think there are risks in moving too quickly. Certainly, there are risks in moving too slowly as well.

The Chair: I'm going to go to Mrs. Towle and put you back on the list, Mrs. Jablonski.

Mrs. Towle: I think he has something more.

The Chair: I'm sorry. Please, go ahead.

Dr. MacDonald: That's okay. I wanted to make a small footnote, let's say, that we did undertake a small trial of vision screening in a rural setting versus an urban setting. Note that Alberta does not have a school vision-screening program to date. We wanted to know just how difficult it would be to do that in rural and urban settings. The school nurses say that they're totally overwhelmed with their responsibilities at the present time and they could not undertake to do an additional task such as just screening for vision. I would say that it was very difficult to undertake this clinical research, and we were unable to show that vision screening in the format that we have would be effective. It was very difficult to do it, and I would advocate that maybe we should look at that as a province, not just for Irlen syndrome.

The Chair: All right. Mrs. Towle.

Mrs. Towle: Actually, you kind of took the question right out of my mouth. I'm literally thrilled to hear that you tried to do that. Is there any way to get a copy of that?

Dr. MacDonald: I could try to find it in my files and bring it forward, yes.

Mrs. Towle: That would be super.

I have to admit that I'm torn because I have a nephew who seems to have had great success with his Irlen lenses. He's in grade 9, and he seems to be flourishing. So I am torn. I'm open minded. I take Ms Notley's point, though, too, that there are a number of other items or other effects on children that we're not mandating. Mental health: we know that's a huge issue, especially, interestingly enough, since I came into this role. The huge mental health issue in rural Alberta and the access to mental health is daunting, so I can only imagine what it's like in urban Alberta as well.

From a physician's standpoint, where do you think the priority should be? If we're going to take a look at mandating a specific area of testing or a specific style of testing, where do you see that the priority should be for this government if we're truly going to get to the issues of how people read, what their vision issues are? Would the AMA be open to including in that the possibility of Irlen's?

Dr. MacDonald: You're asking me directly or the group?

Mrs. Towle: Well, any one of you is okay.

Dr. Sharon: I think it's important, as Dr. MacDonald said, that general vision screening as part of looking at learning disabilities be done, and that's one of the main recommendations that the report also brought out. Again, it's still controversial, having the diagnosis of Irlen syndrome as part of that, but if you put it more broadly, whether people answer certain questions about issues incorporated in that, I don't know if I'd have anything against it. I mean, naming it something that, again, evidence hasn't yet supported is hard for us to support, but having vision screening early on in kindergarten and grade 1 as part of screening for learning disabilities would be very important.

2:30

Mrs. Towle: Right now that's not mandated?

Dr. Sharon: It's not mandated, and, as Dr. MacDonald said, it's also very difficult to implement.

Mrs. Towle: Okay. Thank you.

The Chair: Okay. The information that Mrs. Towle asked for, about the screening in the rural areas: if you could just submit that to the committee through the clerk, that would be appreciated. We can distribute it to all the members. Thank you.

Ms Notley.

Ms Notley: Thank you. I'd sort of like to follow up a bit on the question that Mrs. Towle asked and attempt to ask a question that I asked of previous presenters very, very poorly. I don't think they quite understood what I was asking because I didn't quite know how to ask it. I'm going to try again, and if you don't understand what I'm asking, that's fine. You might not even be able to answer as well.

Just from your expertise, assuming you've got a hundred kids in school who come to you all at once, I guess, which would be a little bit chaotic, with complaints that are typical of what the Irlen syndrome people describe – reading disabilities and problems, and they've never had their eyes tested – and those hundred kids are tested, based on your knowledge, if you have the answer to this, in what percentage of them would you find that the solution is actually with sort of more traditional eye therapy; you know, glasses, whatever? So what percentage of that? I'm assuming that would be the biggest group but maybe not.

After that, what's the next tier or another tier of inquiry that then is launched into to determine the explanation for why these symptoms exist? Then the question is: are there other tiers? Based on any of your collective understanding and evaluation of the research, where does Irlen sort of sit in those tiers? I'm basically trying to get at what Mrs. Towle said more effectively than I, which is that if it's not that the person needs glasses, what is the next most common explanation for what's causing the disabilities and seems to be related to vision problems? I know it's a very awkward question. I'm sorry.

Dr. Sharon: It's a very broad question, with many different answers that are possible. I'm a pediatrician. I see roughly 40 kids a day. When I see them, we will discuss if there are any issues in school, et cetera. Some will come primarily because they have school problems, whether it's reading problems, math problems, et cetera. Vision is an important part in terms of: is there any problem they would need glasses for, or is there any cross-eyedness, anything that would require any correction to help with reading, for example? Once that has been tested – we usually will use an optometrist with a special interest in kids to do that – and it's either been corrected or it's been deemed that it's not playing a role, the school then will do some testing to see if there's dyslexia, as we know that's the main learning disability, or dyscalculia, which is a problem with math. Of the hundred kids you mention, I would have zero with a diagnosis of Irlen. It's not on my list of diagnoses, and it's not on the list of diagnoses of the pediatric optometrists that we work with.

Do I have kids in my practice who have been diagnosed with Irlen by somebody else and who wear filters? Yes. I have two. They were self-initiated referrals and diagnoses by the parent, who felt that the school's test didn't help enough or that the extra remedial teaching they received didn't help enough and where the optometrist said that there was no issue. I've had many of those, but only two of those were diagnosed and are wearing those filters.

Ms Notley: That's helpful. It's a start.

The Chair: Good. Thank you.

Dr. Swann.

Dr. Swann: Thanks very much. I have been concerned that this committee is charged with looking at, identifying appropriate screening testing in a province where we have traditionally and, I think, appropriately let experts and health authorities decide on the basis of evidence what should be screened for and what should be funded by the public purse, and where there's appropriate evidence and resources to deal with positive tests or negative tests, that should be the process followed. However, the committee has chosen to take this approach at the request of a member, and I respect that.

I've also had the experience of an adult who benefited from tinted lenses. I'm in a position, I guess, to ask the AMA and other health bodies about the most likely approach to investigating this and establishing evidence, because there is insufficient evidence in the traditional research. Would they not support a thorough review of those individuals who have been identified with Irlen syndrome who are using lenses, having them reviewed to identify those in which coloured lenses alone have made a substantial difference and those for whom other modalities were actually perhaps more important and where the tinted lenses have been perhaps unnecessary, redundant, and added little once the more pertinent diagnosis and treatment were made? Would you support appropriate screening and testing of those individuals already identified with Irlen syndrome?

Dr. MacDonald: I think that it would have to be an educationalist who would be the one who would be doing the analysis. I can't imagine that the vision and health care professionals, either optometry, ophthalmology, or even family medicine or pediatricians, would be capable of understanding what the effect had been. I think it would be in the realm of education. That would be my personal opinion. You'd have to look at reading speed and other comprehensive evaluative mechanisms. It would be an interesting study. Again, you might come out with an answer that doesn't really show any difference. There might be a marginal difference. You might have the expression that the study was underpowered. I'm not sure that you'd gain much in the process.

Dr. Swann: This is beyond the scope of the committee, but I guess what I'm suggesting is that enough people have had a significant improvement and have made testimonies to this committee that it strikes me that more research is needed and that the locus to focus on is those individuals who have been identified with Irlen syndrome. All I'm suggesting to the committee – again, I have not found this committee to be the appropriate body to review this, but since we are and we're learning about significant numbers of people who feel they have that syndrome and have benefited from lenses, the next step would be for this committee to recommend further research, it seems to me, after we reject this bill. That would entail, I think, most profitably looking at those who've been identified with Irlen syndrome.

That's all I needed to say. Thank you.

The Chair: All right. Thank you, Dr. Swann.

Mr. Wilson.

Mr. Wilson: Thank you, Mr. Chair. Now, I don't read many scientific research papers, but there seems to be peer-reviewed research supporting both sides of this issue. I have two questions that I was hoping you can address. How do you and your organization with your expertise explain the varying outcomes of the research done around Irlen? At the risk of sounding like an Irlen syndrome denier, is it safe to say that the science isn't settled here?

Dr. Lewis: I think that you're exactly right. It's safe to say that the science is not settled here, and that's perhaps the crux of the matter.

Dr. Sharon: We want to just refocus everybody that we're talking about whether or not there's sufficient evidence to screen, and we're saying that there isn't.

Thank you.

The Chair: All right.

Mr. Wilson, did you say that you had another question, another supplementary?

Mr. Wilson: No, Mr. Chair. Thank you. That covered both of them unless they want to address how they can explain the varying outcomes, how there's such widely different peer-reviewed research on both sides of this issue.

The Chair: Go ahead.

Dr. Mittelsteadt: Yeah. I think it's difficult to state that. What often happens in medicine is that you have a group of experts that do a comprehensive review of all of the literature, which is what was done by the American colleges of pediatrics and ophthalmology when they made those statements. To say that they've made an error, you know, I think that you would have to have specific evidence to refute all of the evidence that they evaluated. I think that to speak to the question about differences in outcome and the outcomes of whether the tinted lenses were the factor is difficult as well because often there are other interventions that are going on at the same time. They're continuing to do the reading, testing, and teaching of these particular individuals, and you know, which intervention actually makes the difference is often difficult to decide. But I think none of us as physicians is going to refute that more evidence would be a good thing.

2:40

The other caution I would put in. I sit on screening committees for breast cancer and cervical cancer and have some knowledge as well of the colorectal screening programs in Alberta. I think that even though there's a lot of controversy about screening today, most people would recognize that there is good value in those particular programs. None of those programs has a screening test that has a 90 per cent pickup rate for everybody who is tested. You know, to me, it's not a screening test if you're getting a 90 per cent or a 98 per cent positive rate.

The Chair: All right. Thank you very much.

Mrs. Jablonski, two minutes.

Mrs. Jablonski: Thank you. I would remind you that people are prescreened before they come to those screening tests, so it's not like just taking anybody off the street. They've usually been through all kinds of therapy before.

Anyway, Dr. Mittelsteadt, you mentioned that people who used Laetrile professed it to be a cure, as does the Zamboni method for multiple sclerosis, and I would say to you, in comparison, that I don't think it's a fair comparison because the Irlen method doesn't propose to be a cure at all. It's a noninvasive, nonpharmaceutical procedure that gives a tool to people to help them see better, and it certainly costs a lot less than drugs and surgery. I'll repeat that I'm not willing to sacrifice another generation of children while we conclude the evidence when there's equal evidence on both sides of this controversial subject to show that the filtered lenses do indeed help the children to succeed far better than they were succeeding previously.

Question: would you support the gentlemen – there are a number of them out there – who are optometrists who have developed the colorimeter that's been developed in Great Britain and that's in studies and the new chromograph lenses, that are very similar to the Irlen lenses? These are optometrists that have come out with two other tools that are very similar to the Irlen technique to help people. Would you support their research and their conclusions?

Dr. MacDonald: I don't think any of the group that you're facing understands either the mechanism of those tests or the physics of them. We do appreciate that people wear glasses and that people are sensitive to light and are bothered by flickering lights, especially fluorescent light. There are standards regarding the amount of light that needs to be in rooms, what shielding is present. These lights are not full spectrum, for example. They do not have incandescent within them. It's not in the red spectrum.

The physics of light and how we see is very, very interesting and very complex. I would point out that about 5 per cent of the male population are red-green colour deficient, and they don't have learning disabilities. But that said, the aspect of photosensitivity is definitely present. There are individuals who do better with task lighting, for example, rather than bright overhead lights, and certainly there are individuals now who are looking at a Smart board, which is white, in the classrooms. It's harsh. People don't do well with certain colours.

So there are all sorts of accommodations that are ongoing in our school systems that are trying to bring a proper education towards our children, and if it so happens that they benefit from coloured overlays or tinted lenses, wonderful, but I don't know that the science really is there to differentiate that you should be screening for this, that this is a widespread issue in our general population.

Learning disabilities definitely are widespread in our community. Dr. Sharon and Dr. Lewis are very, very – how would I say? – knowledgeable about learning disabilities. The difficulties of children in our environment now are quite different than they were when we were growing up. I wouldn't minimize the importance of making sure that we have explored as much as we can as to why this child is not learning in school.

The Chair: Great. Thank you. That concludes . . .

Dr. MacDonald: Yeah. I can be quite academic if I get going.

Mrs. Jablonski: I appreciate it very much.

The Chair: All right. Well, thank you very much. We'll wrap it up there. I very much appreciate you presenting here this afternoon. You're free to go, or if you wish to stay and listen to some of the other presentations, you're, of course, more than welcome to stay. Thank you again for joining us.

All right. I'd like to call on Dr. Sharon Vaselenak if she's with us. Great. Welcome.

Dr. Vaselenak: Good afternoon.

The Chair: Thank you so much for joining us. Were you in the room when we did the last round of introductions?

Dr. Vaselenak: Yes, I was. Both rounds.

The Chair: You were? Very good.

I'd like to welcome Mr. Khan. Mr. Khan, thanks for joining us on the phone and then joining us in person. I very much appreciate you being here.

Dr. Vaselenak, we have just a reminder that the microphones are operated by *Hansard*, so there's nothing that you have to do there. The meeting, of course, is open to the public and recorded by *Hansard* and streamed online.

You've got 15 minutes for your presentation and then 15 minutes for questions and answers, give or take, as you probably have noticed. Go ahead any time you're ready.

Dr. Sharon Vaselenak

Dr. Vaselenak: Thank you. Committee members, Mrs. Jablonski, Mrs. Irlen, fellow presenters, and guests, my name is Sharon Vaselenak. I'm a family physician who has practised in Edmonton for 30 years. I am a fellow and national examiner of the College of Family Physicians of Canada. I'm here to represent the human face of Irlen syndrome and, hopefully for you, to try to fit some of its jigsaw-puzzle pieces into a framework that will convince you that this bill is important. It represents a vital step in alleviating a significant learning barrier that affects many children.

This presentation is daunting for me, especially presenting after representatives from the AMA that I refer to. It has taken eight years for me to arrive at this presentation, and in that time I have been bending the ears of educators from kindergarten to university, optometrists, opticians, and colleagues. I'm very thankful that Mary Anne Jablonski has had the courage to propose this bill. I'm also saddened that many children have suffered great frustration in school in those eight years, and I'm optimistic that if this bill is implemented, we can take a step forward in identifying the children that are affected by Irlen syndrome.

I wear many faces where Irlen syndrome is concerned. I have Irlen syndrome. Two of my children have Irlen syndrome. As a family physician in that eight years I have now identified over a hundred patients, including members of their families, who are affected, in some cases covering three generations. This has given me a fairly unique perspective on how the symptoms provoked by this light sensitivity can affect not only a child's school performance but, over their life spectrum, also job opportunities and family relationships. My patients with Irlen syndrome range from five-year-old kindergarten students, who have presented because they blink excessively, to octogenarians in DAL unit rooms, who have insisted on unscrewing the fluorescent light bulbs in their apartments.

The stories are legion, but the one that I can describe best is the one of my family. I myself was diagnosed with Irlen syndrome in 2004. I had always felt that I was more sensitive to light than most people, and I loved my copper-coloured Serengeti sunglasses. However, things changed dramatically for me beginning in 2000, when I relocated to a new medical office, and for the first time in my career I was working in fluorescent-lit exam rooms without windows or skylights. Initially my staff were amused as I tried numerous colours of fluorescent tubes and changed wall colours because I just didn't like how things looked.

2:50

In 2003 our office converted to an electronic medical record, one of the first in the city, and this required me to work on bright, state-of-the-art, flat-screen monitors for up to eight to 10 hours a day. Within months I thought that either I had macular degeneration or diabetic retinopathy. When I looked at the screen, letters and words dropped out. I couldn't tell an "a" from an "o" or a "c" from an "e." There were blank spots on the page. I couldn't remember what I'd just read. I began having headaches and felt exhausted by noon. Then patients' faces started to have blank spots in them, and I found myself struggling to focus on seeing and not listening to their problems.

I shortened my hours. I saw my ophthalmologist. After the fifth redo on my lenses my optician suggested that maybe I should see a new optometrist. Another set of lenses, but my computer issues remained the same. I spent more time double-checking my charts, afraid of making errors, but this only made my symptoms worse. Finally, my staff suggested that I take a few months off until I could come up with a solution, but I didn't know what the problem was. At this point a thousand patients were very unhappy about losing their family physician.

It was exactly at this point that my son required repeat educational screening to qualify for extra time for his grade 12 departmental exams. The psychologist that he saw had recently attended a workshop on Irlen syndrome and suggested that he be screened for that as well. As I looked at the list of symptoms, I realized that I was checking off every one. My problem now had a name, Irlen syndrome, and I had been given the first step in coming up with a solution that enabled me to return to work.

My son's difficulties began in grade 1: being inattentive, falling asleep in class, lagging behind in reading. But he was a boy, the youngest in his class, and was otherwise doing well, so no flags of concern were raised. However, by grade 5 he was over two grade levels behind in reading. While he could get a hundred per cent on his spelling test because we drilled him nightly, he couldn't recognize the same words in a sentence. Reading aloud, he skipped words, skipped whole lines, ignored punctuation. Homework became a battle zone of frustration.

My husband and I, because the school system wait was so long for an educational assessment, decided to pay for a costly psych-ed assessment. We were told that he had a Mensa-level IQ but had an auditory memory impairment. This puzzled me as he could remember every detail of any documentary on the *Titanic*. He learned primarily by what he heard.

Little changed until grade 7, when I got a call from his English teacher. My son had run out of the classroom in tears once she assigned three novels with book reports in the first term. With this amazing teacher's help we modified his curriculum, and he was given extra time for all of his exams until he reached his first grade 12 departmental. That was in math, which he had previously excelled in, and he barely passed that exam.

We were unaware that the school board required another costly psych-ed assessment to allow for extra-time exams, and without this we were unable to apply for the extra time. We did arrange for another expensive psych-ed assessment with the same psychologist that had screened him the first time. The difference this time was that she had recently attended a workshop on Irlen syndrome and suggested that he be assessed for this as well. He tested positive and was placed at the severe end of the spectrum. When he found the balance of overlays that worked for him, I was stunned by the fluency of his reading. For the first time he said that he could actually read from one line to the next. After 10 years we had that important missing piece of the puzzle, both for him and myself.

Implementing some of the suggested strategies was a challenge as many teachers did not understand his need for darkly tinted lenses and a baseball cap for exams. During one final exam he was ordered by the supervising teacher to remove them or leave the exam. My son chose to remove them and stay. Several days later the same teacher apologized and gave him a new baseball hat.

With a lot of hard work, tinted lenses, and some other accommodations my son graduated from the U of A engineering program and is now working as a mechanical engineer.

My daughter was diagnosed the next year after four years of similar reading problems. She has the dubious family honour of having been suspended from junior high at the end of grade 8. Frustrated by her poor marks, she started cutting classes, and when asked by the principal whether she wanted to continue at that school, she said no. When I later discussed my daughter's Irlen screen with the same principal – and her screen also placed her at the severe end of the spectrum – I was told that at that particular academic challenge school the principal preferred not to have to accommodate this type of a learning disability.

With tinted lenses my daughter did well for the remaining four years of school at a different school although I did have to explain that she was not doing drugs but had very dark tinted contact lenses. After high school she chose to volunteer for an HIV program in Tanzania and is now in her third year at the U of A and also volunteers for the Elizabeth Fry Society.

Irlen syndrome also frequently has ripple effects in families. In elementary school my nephew was suspected of having Tourette's syndrome because of his constant blinking. Throughout school he struggled to achieve passing marks and was taking high school remedial classes at Concordia when my son got his tinted lenses. Shortly afterwards my nephew, too, was screened positive. He called me after the first few days of wearing his tinted lenses and described actually being able to focus in class. He went from barely passing to excelling and has gone on to complete a degree in mechanical engineering as well.

My older patients have told me so many similar stories but often not with such happy endings. Often they were labelled in a like father, like son fashion as so often this disease affects multiple generations. They weren't expected to be able to do any better than the parent before them who had been unable to read. Many have a lifelong avoidance of reading. They found school very frustrating and quit as soon as they were able. They were labelled as being lazy, stupid, not achieving their potential when, in fact, they were trying much harder than their peers. They were embarrassed to read out loud, risking ridicule and bullying. They often had low self-esteem. Many felt that they had to settle for jobs beneath their capabilities.

All of these are reasons to try to identify those affected by Irlen syndrome as early as possible in their educational path. The lifetime cost of missing the opportunity to intervene cannot be measured in dollars and cents.

In my era schools had large windows and blackboards. We read from textbooks and wrote on paper. Medical school, for me, was spent largely in the dark with overhead projectors, my perfect learning environment. Today many classrooms are windowless. More learning is being done on computers or tablets that are brightly backlit in rooms with fluorescent lighting. For light-sensitive individuals this can make reading infinitely harder. My daughter was a prime example of this. She would score a hundred per cent on written essays yet could not pass one reading comprehension test on a computer in junior high.

Home environments are also changing as most homes now will move from incandescent to fluorescent lighting. So for these children home will no longer be a safe zone either.

My family and I had the luxury of being able to pursue very expensive private testing, and even with that, it took almost a decade to learn about Irlen syndrome. Because of my profession I could communicate with Helen Irlen and attend international meetings to become more informed. I certified as an Irlen screener to understand the process. I sought technical assistance from computer wizards and last year enlisted the help of an architect to design exam rooms with halogen lighting and solar tubes so that I could work in more comfort. I continue to wear tinted lenses and experiment with my environment. Mostly, I consider myself very fortunate to have learned that Irlen syndrome is a real entity and that there are tools to work around it.

So I am here today as a physician, a parent, and a patient. I am here to advocate for children who have not yet been diagnosed. I know the frustration that they feel when they start a school day with the best of intentions and cannot understand why they can't achieve in the same way as their peers. I understand the anger, hopelessness, and sense of failure felt by parents when they don't know how else to help their child.

3:00

Most families are dependent on the school system to help them identify any possible conditions that may be affecting their child's ability to learn. There are many similarities between family practice and the education system. I understand that teachers can feel overwhelmed by their responsibilities and see Irlen syndrome as one more thing that they have to deal with, but it can actually make their job easier and much more gratifying. If each year a teacher can identify one child in a classroom with Irlen syndrome, they can change that child's educational future immensely, and the ripple effect can continue to benefit siblings, cousins, and friends.

Unfortunately, I also understand the reluctance of the involved professions, especially my profession, to learn about Irlen syndrome. I recall the first child that I met with Irlen syndrome years before I was diagnosed. She was a child affected by fetal alcohol syndrome, with many behavioural issues, and when she proudly showed me her orange-tinted lenses, it just didn't seem like something that I needed to know about. I had no idea that the same sensitivity was affecting my son and daughter. The information was out there; I just didn't get it.

While slowly more professionals are being exposed to this diagnosis, it is criticized as being a diagnosis from soft science, considered less important as it comes from an educational psychological background with limited research-based evidence. The idea that light can provoke physical symptoms and impair visual perception is a hard concept to imagine if you have not felt it. This is changing, but with no pharmaceutical company investment or other treatments that could reap large profits, this will take time.

However, historically in medicine many syndromes have been defined and treatments attempted long before their pathophysiology has been determined. Entities such as depression, fibromyalgia, PMS, and complex regional pain syndromes have no specific lab tests that I as a physician can order, yet I do not hesitate to make these diagnoses or treat them primarily based on the patient's description of their symptoms.

Irlen syndrome has a valid screening tool and applicable treatment strategies that are simple and beneficial, as acknowledged by thousands of people world-wide. This is not a panacea diagnosis for any child with a reading disability. It is a very specific entity and requires screening by an individual who has been trained to evaluate the symptomatology in a child. It is not enough to just lay colour transparencies over a page and see what happens.

My hope is that if Bill 204 is passed, many more professionals, especially educators – and I would consider physicians to be educators – will become interested in learning more about Irlen syndrome. They are so important in minimizing any delay in identifying children who can be helped. The cost of missing this diagnosis in a child is so high and the tools to help them succeed in school relatively simple.

Recently in speaking with my optician and optometrist about this bill, both commented that maybe it's time for them to learn more about Irlen syndrome. It's human nature for us to put things on the back burner until something challenges us to take action. As a physician, a parent, and a patient I believe that this bill can be that motivation.

Thank you.

The Chair: All right. Well, thank you for sharing that personal account of what this has meant for you and your family.

Dr. Vaselenak: Questions?

The Chair: Questions. Mrs. Jablonski.

Mrs. Jablonski: Thank you very much, Mr. Chair.

The Chair: We're going to get fairly quickly to a question this time, right?

Mrs. Jablonski: Yes. I'll try.

I have three questions. First of all, I just want to say thank you so much, Dr. Vaselenak, for being here today with us. I think that your presentation was very courageous and brave because as you sat down, you did realize that you were going to be saying things that were opposite of the very distinguished gentlemen who had sat there before you. But you've lived through it and you've experienced it. You've seen the great results. I just want you to know how much I appreciate that you're here.

Dr. Vaselenak: Thank you. I feel that it's important enough that I had to. I'm not politically inclined at all, but it was time to come out of the box with it.

Mrs. Jablonski: Well, thank you. I don't think this is political. I think this is all about our kids.

Dr. Vaselenak: That's why I'm here.

Mrs. Jablonski: That's why I'm here, too. Thank you.

Three questions. First of all, I've heard people say directly to me, to Helen Irlen, and to other people who understand that the Irlen process saved their life. There was a 50-year-old woman who was hopeless, and then somebody suggested: well, maybe you should go this route. She said that it saved her life. Another family said: you changed our lives and made life more livable. Another family said: you made our family whole. My first question. Or do you want to wait for three of them?

Dr. Vaselenak: One at a time. I can't focus that far.

Mrs. Jablonski: He might cut me off.

The Chair: Just one at a time, but shorter preambles.

Mrs. Jablonski: Okay. Thank you. No more preambles.

Do you think those are exaggerations?

Dr. Vaselenak: No, I don't think they're exaggerations. I know what our life was like at the point in time when all three of us were struggling with trying to figure out why we couldn't function at the level that we should be able to. It wasn't that simply putting coloured overlays and tinted lenses in front of us solved every problem, but identifying that this was a real entity that had been described and where other people had been successful in finding solutions made a huge difference psychologically, to know that it was not a figment of my imagination that I could not work on the computer.

The other thing that I didn't mention was that during that interval I quit reading. I couldn't read anymore, even a paperback book. I couldn't process what I read. It was like my brain was just done by days of working on the computer. So, no, I don't think those are overexaggerations.

Mrs. Jablonski: Thank you.

My second question is that we've heard that the screening costs for Irlen's are astronomical. You mentioned that someone in your family had to undergo expensive ed psych assessments. A screening is around $200. I wonder how much an ed psych assessment is worth.

Dr. Vaselenak: The ed psych assessments at that point in time – and we did three of them for my children – cost approximately $2,500 each.

Mrs. Jablonski: Two thousand, five hundred dollars each. That would be more like astronomical.

My third question. I'm so grateful that you are a family physician and you recognize the symptoms, but how do you determine when one of your patients comes in that they might need a screening or testing for Irlen?

Dr. Vaselenak: I'm at a point in my practice where I see relatively more people in my own age group as opposed to children, although some of my patients are now having children, so I've become more familiar with the symptoms that present in adulthood. A lot of them involve headaches, fatigue, difficulty working on computers. It still amazes me that on a weekly basis I will usually pick up on one or two people, especially if I'm covering for some others. My most frequent tipoff is the fatigue at the end of the day at work.

Mrs. Jablonski: Thank you very much, Dr. Vaselenak.

The Chair: All right. Any other questions? Mr. Khan.

Mr. Khan: Thank you, Mr. Chair, and thank you very much, Dr. Vaselenak. Your testimony today was extremely compelling. I'll just make an aside that as a parent you must be very, very proud of your children.

Dr. Vaselenak: I am. Thank you. But I don't know which parents aren't.

Mr. Khan: True enough.

I've been en route, and I've been listening over the phone. Actually, the question I'm going to ask you is a question that, had I run faster up the stairs, I would have asked your colleagues, the doctors who testified previous to you. As you said, you've sort of approached this issue as a parent and a patient and a doctor, so I'm going to ask if you could put your doctor hat on for a moment, your family physician. Part of the challenge, I think, for all of my colleagues as we examine this issue is that we've gone through and read the materials and read the studies and that we have studies that say Irlen syndrome can't be proven and that it's soft science and it's inconclusive. Then we can read studies that say that it's every bit an issue, and it's been proven, and it's a neurological issue, and there's a cure, there's a solution to it. So it's a real challenge for my colleagues and I to sort of wade through those disparate opinions.

3:10

My question to you is as a doctor having been familiar, as I'm sure you are, with both sides of the equation when it comes to the studies. There are countless patients who have been diagnosed with Irlen's who are being treated with the lenses and have received phenomenal results. As a medical professional who's trying to look at both sides of those studies, how much weight do you actually put on the incontrovertible results of the lenses for people who have been diagnosed with Irlen's?

Dr. Vaselenak: I think that a lot of the difficulty lies in that Irlen syndrome is a spectrum. It's similar to – it's not an allergy, but in some respects there are parallels, like asthma, where if you have some people who have very mild symptoms, they can be exposed to, you know, an allergen or something that might trigger some symptoms in them, but overall in their day-to-day life they function. They know that they have to avoid cats, and they're fine. There are people with Irlen syndrome like that. They learn intuitively that they don't like certain lighting environments, that they don't like working on a certain computer monitor. If they can avoid those things, their symptoms are fairly minimal.

Then you have those that are on the far end of the spectrum like my children and like myself when my environment changed, where all of a sudden your symptoms become dramatically worse and have a huge impact on the day-to-day functioning in your life. It's a much broader entity than only affecting reading. It truly is a visual-perceptual disorder, but for this application its impact on reading and the effect that that has on the rest of that individual's life for school performance, occupational performance, and success in jobs is huge. I think that's what makes that hard to measure because even in an individual person their symptoms can be made better or worse depending on their environment.

Mr. Khan: Thank you.

The Chair: All right. Well, thank you again for your presentation this afternoon and for sharing your personal story. Thanks very much.

I'll invite the presenters from the Alberta School Boards Association to join us at the table, please. For everybody's information we'll have a short break after this presentation and Q and A.

Mrs. Hansen: Good afternoon, everyone. My name is Jacquie Hansen. I'm the president of the Alberta School Boards Association. With me today are my colleagues Grace Cooke, who is a lawyer with the Alberta School Boards Association, and Colleen McClure, who is the associate superintendent of Greater St. Albert Catholic schools. Colleen's main job is to ensure that kids, particularly vulnerable kids, kids with diverse needs, have their supports and services taken care of.

The Chair: Jacquie, I don't think you were in the room when we did the introductions around the table, so I'm just going to very quickly do that so you know who you're presenting to if that's okay. We'll start over here on my right.

Mr. Reynolds: Hi. I'm Rob Reynolds. I'm the Law Clerk at the Legislative Assembly.

Ms Zhang: Nancy Zhang, legislative research officer.

Ms Leonard: Sarah Leonard, legal research officer.

Ms Robert: Hi, Jacquie. Nancy Robert, research officer.

Ms Notley: Rachel Notley, MLA, Edmonton-Strathcona.

Mr. Khan: Hi, Jacquie and Colleen. Steve Khan, MLA, St. Albert.

Mrs. Leskiw: Genia Leskiw, MLA for Bonnyville-Cold Lake, and a former teacher of 37 years.

Mrs. Jablonski: Good afternoon and welcome. Mary Anne Jablonski, MLA, Red Deer-North.

Ms Cusanelli: Good afternoon. Christine Cusanelli, Calgary-Currie.

Mrs. Fritz: Hi. Yvonne Fritz, Calgary-Cross. Welcome.

Dr. Massolin: Good afternoon. Philip Massolin, manager of research services.

Mr. Tyrell: Good afternoon. Chris Tyrell, committee operations.

Ms Rempel: Jody Rempel, committee clerk.

The Chair: Dave Quest, Strathcona-Sherwood Park, chair of this committee.

If our members on the phone could just quickly introduce themselves, please.

Dr. Swann: David Swann, Calgary-Mountain View.

Ms Kubinec: Maureen Kubinec, Barrhead-Morinville-Westlock, standing in for Matt Jeneroux.

Mr. Luan: Jason Luan, Calgary-Hawkwood, standing in for Steve Young.

Mrs. Towle: Kerry Towle, MLA, Innisfail-Sylvan Lake.

Mr. Wilson: Jeff Wilson, MLA, Calgary-Shaw.

Mr. Pedersen: Blake Pedersen, MLA, Medicine Hat.

The Chair: Kerry, it's like magic. You were just here. You're everywhere.

All right. Just to remind the presenters, the microphones are operated by *Hansard*, so there's nothing you have to do with those.

The meeting is open to the public, of course, and recorded by *Hansard* and streamed online.

You get 15 minutes for a presentation, 15 minutes for Q and A. Please go ahead.

Alberta School Boards Association

Mrs. Hansen: Great. I don't think that we will be that long, but we'll be happy to answer any questions.

The first thing we'd like to say is that we certainly believe in the intent of what this bill is trying to do. For us, when we look at this proposed legislation, it talks about supports for kids, and really that's what we're all about.

The Inspiring Education document, the document that all educational partners are working towards achieving, states that we need to be meeting the needs of all of our learners, all abilities, wherever they are on the spectrum of learning. It states:

> Every learner should have fair and reasonable access to educational opportunities regardless of ability, economic circumstance, location, or cultural background. Their needs and ways of life should be respected and valued within an inclusive learning environment. Some learners will require additional, specialized supports to fully access these opportunities.

For school boards this means enabling our educators to determine what the necessary steps are for any student to be successful. The ministry has recently laid out a clear mandate to school districts in a letter to our superintendent stating that we exist to ensure that all children and students, particularly the most vulnerable, have the supports they need to be successful. School boards would concur with this statement.

There are many children that come into our system that present with a spectrum of learning disabilities, and the reasons for this are many. They're academic, they're emotional, they're social, and they're medical. When the educator determines that there is a learning gap and assesses it, the parents are brought in to further determine ways to work together to help the child succeed. Every case is different, as you know, and every learning challenge is usually on a continuum spectrum of whatever their challenge is.

We believe that this particular bill is too prescriptive and, really, that it is contrary to the spirit of the new Education Act, which is meant to be enabling for educators to meet the needs of all students regardless of the diagnosis. We also believe this bill is contrary to the spirit of Inspiring Education, which is based on accommodating any child with the necessary supports, again regardless of the diagnosis.

We are striving for supports for all children in all circumstances. School boards and educators do not want to have to come up with a diagnosis in order to get supports for kids in their class. The supports need to be well in place before a medical diagnosis might be determined. Their job is to identify the extra supports that are indeed needed, to work with the parents for strategies as well as with the appropriate staff, and to explore solutions. Working with parents and guardians is paramount to the process.

From a practical point of view, it would be difficult and costly for school boards to screen every child that presents with a learning disability in literacy. Do we want our kids getting screened and then perhaps labelled with a syndrome, or do we want to be the educators that identify a learning gap and explore solutions so that the student can experience improved curricular outcomes in a timely manner?

We support the minister's submission to this bill as it relates to the Alberta College of Optometrists in supporting any technology that we could use to identify needs. We share his caution regarding the introduction of further responsibilities to teacher time, especially as they are related to diagnosis. The educator's job is not to medically diagnose; the educator's job is to improve learning outcomes.

3:20

We also believe that the identification of learning needs is happening every day in our classrooms and that our kids would be well served by legislation that is inclusive and encompassing. We believe that the new Education Act is encompassing and inclusive. Educators working with parents can identify when children need a spectrum of supports and services, and the Education Act says that we must do that. I can tell you that many, many students come to school and present with learning disabilities. The educators play a key role in determining what the gap in learning is and then putting in place the supports necessary. This is the job of the teacher. As school boards we want to support our teachers in their work for each and every student.

Again, we believe any legislation needs to be enabling, encompassing, and not prescriptive. Thank you.

Now I would invite my colleague Colleen to speak unless there are questions for me. I'm not going to have Grace speak unless there are questions for Grace specifically.

The Chair: I think we'll just get Colleen to carry on, please, and then we'll take questions after.

Ms McClure: Thank you for the opportunity. As a school authority we are very mindful of our duty to accommodate a range of learners' strengths and needs and to provide a continuum of supports and services in schools. As educators we have a responsibility to know our learners, communicate and collaborate with others, and provide the continuum of supports and services students require to access learning. We appreciate policy that is inclusive and enabling, and we support innovation and collaboration. The guiding principles articulated in Inspiring Education support our dedication to ensuring that students have fair and reasonable access to educational opportunities.

In our district we provide for a continuum of universal, targeted, and intensive individualized supports and services in core areas, including assessment of and for learning, differentiated instruction, technology for learning, supporting positive behaviour, engagement, citizenship, and faith formation. We work in partnership with parents, students, and members of our school learning teams to identify students' strengths, needs, and the adaptations and accommodations they require to be successful.

Thank you.

The Chair: All right. We'll go to questions if you're finished, starting with Ms Cusanelli, followed by Mrs. Jablonski.

Ms Cusanelli: Thank you very much for being here today. I think that what you have put forward with your presentation is pretty pertinent for us to be able to differentiate whether or not this piece of legislation belongs as is and if it will effectively really be the precursor to allowing students to achieve their best in school.

I think that what you have identified is that students' learning needs are the responsibility of the teachers. When we talk about assessment, though, this was a question that I guess I came up with at the very beginning of all of the presentations because of something that another speaker mentioned. While we want to look at reading assessment in the classroom, while we want to make sure as teachers that our teachers identify the learning needs and learning gaps of their students – and that is very much their responsibility – when we talk about psychological assessment, I think that's where, in my opinion, this legislation gets a little bit touchy because what we're talking about is an assessment piece which doesn't belong in the role of the teacher in terms of assessing a student for official diagnosis.

Do you think, as was presented earlier – you weren't here, so I'll just let you know. Dr. Penny had said before that it takes two years because of budget cuts in order for a student to be assessed, to be given an actual psychological assessment. I wanted to clarify if, from your perspective, you felt that was the case. I know certainly from my background as a teacher, as a principal, as a resource teacher, having a master's degree in psychology, that that's never been my experience. Students have always been assessed based on need. That need obviously is identified through documentation, through consultation with teachers, obviously, other personnel on staff, and with parents, and often that will take a fairly long period of time. It has never been my experience as a professional that it would take two years because of budget cuts. Therefore, I kind of want to ask you that question.

Mrs. Hansen: I'll let Colleen answer that, she being the on-the-ground field worker.

Ms McClure: Yes. Thank you for the question. I can only speak to what occurs in the district I'm currently employed by. We go through a process for assessment. We're blessed that in our school learning teams, that consist of principal, assistant principal, counsellor, and learning support facilitator, some of our counsellors and learning support facilitators are registered psychologists. I have two who work on the district team who screen the referrals coming in, and then we contract out to a number of psychologists, depending on the need of the student. We have gotten to know a number of psychologists who work well with us. So, no, it is not taking that long at all.

Is a full educational/psychological assessment required for every student? No. For many students we're using some universal screening like Fountas and Pinnell and identifying where they are in their literacy, and they're doing very well with small-group instruction at their level. It very much depends on what the needs of the student are. The measure for us in school is: is the child achieving the learning outcomes? Are they being successful? That's our measure.

Ms Cusanelli: As a supplementary, I guess, just a very easy yes or no: do you believe that it is the role of the teacher, then, to prescribe to parents that Irlen syndrome be tested for?

Ms McClure: I think the role of the teacher is always to communicate with parents and with the school learning team – remember that in our schools we have a special educator, a counsellor, a principal, assistant principal, lead teachers – to communicate with the team: "I'm concerned about a student; they're not learning in the way I have typically experienced students learning," or "I'm concerned that a student is telling me she has headaches all the time." It is to convey that concern. We always very respectfully approach parents in saying: have you discussed this with your physician? We would never prescribe that; that is not our place. But we can ask families: have you considered discussing it with your physician, and might we help you with some observations that we have gathered in the classroom?

The Chair: All right. Thank you very much.
Mrs. Jablonski.

Mrs. Jablonski: Thank you very much, Mr. Chair. Thank you very much for your presentation. It was actually very enlightening, and I sure wish that Minister Jeff Johnson was here. He'd be so proud of you.

Mrs. Hansen: Not always.

Mrs. Jablonski: First, before I ask questions about your presentation, which I thought was very well done, I would draw your attention to studies that I think you should be aware of. The Acushnet public school study – I want you to know about it – was a study that was done with 16 students, special-ed kids that were having trouble reading. The average cost of a student in the school system is around $6,765. When you have to add the special ed because they're having problems, it's $13,471 in that area, anyway. I think it's similar here.

Anyway, the school board paid a thousand dollars for the training of two educators and the overlays that helped the 16 kids that they tested. After they saw the results of the savings that they were able to accomplish, which in that one school district was $108,000 because they no longer needed the special ed because they had the overlays which helped them to be the best that they could be, they went on to test another 108 kids, and they were able to save that one district $732,000. I would draw your attention to that because I think that's really important.

I really liked what you said about inclusive and encompassing legislation.

3:30

You said that Bill 204 is too prescriptive, and after hearing what you said, I think I would agree with you. Hypothetically, if Bill 204 had recommendations from this committee, for example, to be inclusive and encompassing about teachers talking to parents about the gaps that they see in learning but to include things like dyslexia and Irlen's – I've got to tell you that teachers readily say, "Oh, I think he has ADHD; I think he or she needs Ritalin," so that's a little bit like prescribing. Not that I encourage that, but I would say to you that if this bill were to be all inclusive and encompassing and mention things like dyslexia and Irlen, would it be more acceptable to you?

Mrs. Hansen: Coming from a school board, I'm talking a little bit about: this is governance, and this is policy, and these are rules that we need to live by. Honestly, what we get concerned about is that if we start to name certain situations, name certain things that are happening to kids – we have autism; Asperger's; vision, hearing, and sensory disorders; lots of things that we can't even name because they don't have names yet – we're going to exclude a group of kids if we are naming certain syndromes. That is absolutely with no disrespect to this particular challenge, because this is challenging. What we feel is that we need to have the supports in order to have those conversations with parents, to discuss exploration in solutions and strategies, and have the supports within health care and wraparound services to be able to do whatever it is we need to do to support that child.

I know this because I have a child myself that has never fit into a medical box. I have told my story a million times to a million different people, and at the end of the day we have some managing to do with him. He's never been fully diagnosed. I think that putting this into law doesn't necessarily help us. What would help us is if we had 36-month screening and early intervention for some of our kids so that we know the motor skills, the vision, the auditory for kids before they even come to kindergarten. We know things like: a hundred per cent of children in juvenile-delinquent homes have hearing problems. A hundred per cent. Why aren't we screening them at 36 months? Why don't we have things like that in place?

I just think that putting things into law doesn't solve our problems. When we're going to pick a syndrome and put it into law, I think that's great for that particular syndrome, but who will we exclude when we see so many children coming into our school systems with complex needs beyond our belief? That's the impassioned part of my speech. This is a very serious syndrome – I don't take that away from anybody – and we have a lot of work to do for a lot of kids under a lot of stressful circumstances, and we need to get to it.

The Chair: A supplemental but short, please.

Mrs. Jablonski: Sure.

Thank you very much for that – that was very passionate – and I totally agree with you. If this is just one of the syndromes that we need to pay attention to or to become more aware of, then let's become more aware of this one but take into consideration the other things that you've just said.

I can tell you, too, that there was a study done in the United States on juvenile offenders. There was a study done, and it showed that 82 per cent of all juvenile offenders could also not read. Whether that was part of a hearing problem or part of an Irlen's problem, who knows? But you're absolutely right. We need to be testing more. I would say to you that a psych-ed assessment, that costs $2,500, is a pretty expensive assessment when you compare that to a screening for Irlen's, which is around $200. If you can save $732,000, then you can do more for all the other kids, too. Yes, they all need to be helped and supported, and I thank you very, very much for recognizing that.

Thank you.

Mrs. Hansen: Thank you.

The Chair: All right. Ms Notley, followed by Mrs. Leskiw, please.

Ms Notley: Thank you. I appreciate your last comments. I found your last comments particularly compelling. When you were talking initially, I was like: I don't really think I'm quite there with some of what you were saying. But with what you said most recently around the need to do all this, like 36-month screening, I mean, you're so right. You're so right there. It actually kind of leads into a little bit of what you said before. You talked about how teachers are focused on providing proper support and that that's what they need to do to get the best learning outcomes, even prediagnosis.

But I would say to you that that kind of talk is sort of on one end of the spectrum, because we're talking about spectrums, and that legislating Irlen testing is on the other end. I would suggest that most teachers, even though this is Setting the Direction language – you may or may not know, but I'm quite vehemently opposed to much of what is encapsulated within Setting the Direction. It assumes that a teacher is able to provide appropriate behavioural supports for a child that's got major behavioural and learning problems in the school regardless of whether that child is diagnosed with PTSD, ODD, or Asperger's.

In fact, the behavioural strategies for each of those kids is going to be different based on that diagnosis. The fact that in some cases kids are waiting a very long time to get those diagnoses does negatively impact the teachers, and the teachers are not able to accommodate in the meantime. We have a problem in that many of the teachers in the system right now really only have one class in special-needs education, and that's not enough.

That being said, going back to assessment, that's why I do think assessment is important, but I want to step back a bit from the specificity. I'm wondering if you can tell me a little bit just to clarify. We've talked a lot about these $2,500 psych-educational assessments. I know many people who've just paid for it out of pocket because it's not happening in the school system. I'm wondering if, in answer to my first question, you can tell me a little bit about what the rules are and the criteria around a child being eligible to have the full range of the $2,500 test, which is the full-meal deal set of tests that kids might get if they're having trouble quite young.

Then the second question is: what is the status of vision assessment, as far as you're aware, in the school system at this point? When does vision assessment happen? Is it across the board, or is it only as needed? I know that EPSB, for instance, has vision consultants, but it's very hit and miss.

Mrs. Hansen: I can answer that one. In terms of vision there is no policy in place that children have to have their eyesight tested. What we do know is that there are issues with eyesight that can be caught at birth, and we're not even doing those tests right at birth. We would hope that we could at least get the 36-month assessment. We would also like to see – I don't think we have this in ASBA policy; we've talked about it – that children would have had an eye test before they come into kindergarten. That is not a policy, though, and perhaps not in every school district. They might encourage it, but there's nothing that has to happen, so it is hit and miss. You're right.

Ms Notley: And the ed testing?

Ms McClure: With regard to the ed testing one thing that I can say – and perhaps we're an anomaly – is that I sign off on the invoices for those tests. Typically that would include an assessment report and debriefing, and I have signed off on invoices anywhere from $750 to $1,500.

We do have a referral process for level C assessments. Last year I accepted all of the ones that our educational psychologist recommended be pursued. We look at other forms of testing, too. Sometimes other testing is more appropriate. Something that I'm very mindful of is putting a child through hours of testing. We want to be sure that we're going to be getting information that's really going to be helping us with educational and behavioural programming.

Ms Notley: So in your place you think that the need is met? Is that across the board? That's not my experience and the experiences of people I know, but I'm just curious of what your understanding is across the board in terms of that need being met, the educational testing.

Mrs. Hansen: I think that there is an acknowledgement that this is a very expensive endeavour, and school boards are looking for innovative ways to assess and come up with answers without putting kids through the full testing. I think that's widely known. There always are some difficulties in getting some services. I know that sometimes it's hard to get speech pathologists in. Even though there is money there to do that, we can't get them in. There are always some challenges that school divisions around the province have, but they vary from district to district.

The Chair: All right. Mrs. Leskiw and then Dr. Swann if we have time.

Mrs. Leskiw: Would you not say that with testing, we don't have that luxury in rural areas like they do in St. Albert Catholic or in Edmonton? Would you not say that one of the problems with testing in rural Alberta is that on top of the costs of the psychologists and everybody else, you also end up paying for kilometres to get to place A, place B, place C?

3:40

Mrs. Hansen: You know, I don't know how those contracts play themselves out, but I would imagine that you're probably correct on that.

Mrs. Leskiw: The other question. Over the years of teaching I found that different diagnoses come and different diagnoses go. When I first started teaching, I don't think people even knew what ADHD was. Kids went through it, and there ended up being behavioural problems and so on, and they weren't diagnosed. Not just that but everything else, and as we learn more about a symptom, whatever that may be, then we as educators try to address those needs. Would you not say that Irlen fits into one of them? It's something new, and because it's new, we don't want to embrace it, just like we didn't embrace ADHD.

Mrs. Hansen: I wouldn't say that we don't embrace it, but perhaps there is a lack of knowledge out there to look into Irlen syndrome, and maybe it's something that we need to, you know, get out there more in terms of just: this is a possibility if you're noticing these symptoms. I mean, we're here today to say that we don't believe that this needs to go into legislation. That's really our bottom line, that we believe this is too prescriptive. It's not that we don't believe that these supports should happen. We absolutely believe supports need to be pursued regardless of what the child is appearing to present.

Mrs. Leskiw: My last question: if a teacher is familiar with this syndrome and says to the administrator, "I really believe Johnny would really benefit from being tested because I've tried everything else and nothing has worked, and I think it's worth it in Johnny's case to be tested for Irlen syndrome," what would you say then? Would you as St. Albert Catholic encourage that parent to go out and get tested for Irlen's?

Ms McClure: We would certainly be talking with the parents and consulting with them, and we wouldn't necessarily send them off to do it. We would look at our own assessments and what we typically do, and we would be very open and receptive to any suggestions they might have. We work in partnership with parents, so we wouldn't be closed minded.

I think that in education – I started 32 years ago. I know you're thinking I'm kind of young to have started 30 years ago. No, you're not. I think that we have learned in education to be very open minded, because parents were telling us things 30 years ago that we now know . . .

Mrs. Leskiw: As true.

Ms McClure: As you described about ADHD, autism spectrum disorder, fetal alcohol spectrum disorder, we now know that what those moms and dads were telling us was very accurate, so we've learned to be very open minded.

Mrs. Leskiw: It took 30 years to be open minded on some of those things.

Ms McClure: It did, which is too bad, yes.

Mrs. Leskiw: Thank you.

The Chair: All right. Dr. Swann, if you can keep it fairly brief, please go ahead.

Dr. Swann: I will. I appreciate your comments very much, and I think you've answered all the questions that I had about this, so thank you.

The Chair: Great. Thanks very much. Time is up.

We're going to take a five-minute break. I realize that for this room to empty and fill up in five minutes is going to be challenging, but at the very least if I can have the members out and back in five minutes so that we can proceed with the Irlen presentation. We'll get the audio set up, and we should be ready to go in five.

To those that are on the phone: if you can stay on, please, rather than out and back because, of course, that gets a little bit distracting. Thank you.

[The committee adjourned from 3:44 p.m. to 3:54 p.m.]

The Chair: All right. If we could get all of our members back to the table, please. Now, the next, and final, presentation. Mrs. Helen Irlen and Dr. Sandra Tosta. Dr. Tosta will be video conferencing from, I think, Long Beach, California.

Mrs. Irlen: It's Pasadena, but that's close enough.

The Chair: Pasadena but close enough? Okay.

So we'll do Helen's first, then, and Dr. Tosta's, one after the other.

Then we'll go to, of course, questions and answers. So I'm going to assume around seven, eight minutes for each or however it works out, for a total of 15 if that works.

Mrs. Irlen: Okay. Can I just introduce myself first, or does that count?

The Chair: We'll do that. You've been here the whole time, so you're familiar with who's around the table and on the phone. Yes, if you could just introduce yourself.

Mrs. Irlen: I'll just do a little bit of background just so that you know in terms of your questions. I am a researcher. I did three years of research for the National Institutes of Health. I have been a school psychologist, an educational therapist, a therapist, an adult learning disability specialist and have created programs for adult learning disabilities, including other things along the way. Okay. I was dying to answer.

Dr. Tosta – I'll just introduce her – has a PhD in educational psychology and also has done research.

The Chair: Very good. Well, welcome to both of you.

Dr. Tosta: Hello.

The Chair: Please start whenever you're ready.

Irlen Institute International Headquarters

Mrs. Irlen: I'd like to say that we're honoured to be here today and would like to thank the committee for giving us the opportunity to correct misperceptions, inaccurate information, and to provide missing information in the hope of bringing clarity to this issue. Throughout this presentation we're going to be referring to your packet.

Let's start out with this. Irlen syndrome is a visual-perceptual processing deficit and problem as are all processing deficits with the brain. As you've heard before, 80 per cent of the information we receive is visual and is processed and interpreted by the brain. You actually see what your brain wants you to see. For certain individuals their brain has difficulty processing visual information correctly, and this is called a visual-processing deficit, which is recognized by educational systems, psychoeducational and neuropsych testing, DSM, CPT codes, and qualifies an individual for special education. Irlen's is considered a type of visual-processing deficit. Individuals with Irlen's have a genetic predisposition towards certain environmental factors, primarily lighting, especially fluorescent lighting, high-contrast black print on white, demand for attention and concentration, which causes the brain to have difficulty then processing visual information. You should be aware that these factors that I described are the classroom environment. It is these individuals whose reading and other academic skills benefit from using colour.

Irlen's has an international professional advisory board that consists of eminent neuroscientists, researchers, ophthalmologists, optometrists, medical doctors, and dyslexia and autism specialists. The Irlen method has become an accepted low-cost assistive technology used world-wide. Educators, psychologists, OTs, language therapists, optometrists, ophthalmologists, and MDs have been trained in the Irlen method throughout the world. We've highlighted a few of the key countries I'll be talking about, but in addition, training to become Irlen screeners is ongoing in a multitude of other countries, including Greece, South Africa, Hong Kong, Jordan, Germany, and Switzerland. The Irlen method is used by professionals in universities, colleges, community colleges throughout the world. The Irlen method is not new. It has been around now and used for over 30 years.

We'd like to highlight what's happening in certain countries. In the United States coloured overlays can be used for all classroom testing, standardized testing, and entrance exams for college, law school, and medical school. Over 10,000 educators have been trained as screeners. Why? Because it does save school districts money. We have a letter, which we presented to you, which documents the fact that 46 per cent of students did not need more expensive assistance such as special education services, readers, oral textbooks on tape, note takers, and other accommodations if they were provided with coloured overlays. Massachusetts has a bill very similar to the Alberta bill, which now has passed its first committee reading, and we have just learned that the governor of Mississippi is going to be implementing Irlen screener training in school districts throughout the state.

In the United Kingdom Irlen's is a recognized disability, and as such, the government pays for Irlen assessments and spectral filters for university students. The U.K. navy policy provides for Irlen screeners at navy-based learning centres and funds for Irlen assessment and Irlen filters.

4:00

In New Zealand, where many optometrists are trained as Irlen diagnosticians, the Rotorua Principals Association has endorsed a project, which is ongoing since 2006, where all children starting at age five and older are screened and, if needed, provided with coloured overlays.

The largest eye hospital in Brazil, which has 26 ophthalmologists, has been doing research, investigating the efficiency and efficacy of the Irlen method and the use of coloured filters for the past five years. We just got information. You were presented with a new paper regarding just one of the research projects and the results that they are finding. They have received a grant to train 300 teachers in every state in Brazil in addition to the 200 teachers already trained as Irlen screeners. That's at many universities. We didn't list them all.

Irlen syndrome is a real phenomenon. There has been some doubt cast as to whether Irlen syndrome is real. Research from a variety of disciplines in addition to what has been mentioned previously supports the existence of Irlen syndrome. This includes, interestingly enough, research from highway safety, incarcerated populations, U.S. military studies, educational, biomedical, and neuroscience research.

Highway studies: highways are really concerned with readability and legibility. In 1970 New Zealand did a study that discovered that when you put black letters on white highway signs, parts of the black letters disappeared. As a result, countries all around the world replaced their highway signs, so they now have green or blue backgrounds. Yet we are ignoring this information in terms of its implication for education. I have wondered why it was felt that this would only happen on highway signs.

The U.S. Navy has done two studies, funded by the U.S. Navy, to document that Irlen is real and to show the improvement in reading skills with coloured overlays. I'd like to point out that the key researcher in one of these studies was an ophthalmologist.

Go ahead, Sandy.

Dr. Tosta: I'm going to continue with Mrs. Irlen's point that Irlen is a real phenomenon. In addition to the research that she just pointed out, there are studies that have already confirmed a hereditary link, identified biochemical and genetic markers, and uncovered the anatomical differences in the brains of individuals with Irlen syndrome. There is also a wealth of research with sound methodological design that shows improvements in areas of reading skills, physical symptoms, and academic and workplace success with colour.

While concerns have been raised that coloured filters simply mask eye co-ordination or other optometric issues, in actuality the research that's out there has shown that binocular and accommodative anomalies are not the underlying physiological basis of this condition. In fact, those issues can occur in conjunction with Irlen syndrome. So you can have eye problems and need to visit your optometrist or your ophthalmologist, and you can have Irlen syndrome, and both of those issues should be treated appropriately.

Improvement with colour is not a placebo. Long-term follow-up studies report continued improvement with colour after periods of six months, 20 months, and even up to six years. There are several double-blind, placebo-controlled studies that also show positive results. Most importantly and most recently, advanced brain imaging technology has been able to show the normalization of brain function when individuals are using their optimal colour. This is so important.

I want to talk a little bit more about the brain research. Researchers have utilized functional MRI, visual evoked responses, MEG technology, and SPECT scans to show how brain functioning changes for the better with colour filters. We describe five of these studies in a bit more detail here. I'm not sure if they're on your screen, but they're also in the presentation packet on page 15, so if you want more information, you can refer back to them.

In your handouts we've included letters from several of the principal investigators on these brain research studies, so you can read in their own words how they describe their experiences researching Irlen. Dr. Joseph Annibali, who is one of these researchers and also happens to be chief psychiatrist with the Amen Clinics in Washington, DC, says in his letter: "We have studied Irlen Syndrome using specialized brain SPECT imaging. Our studies show that use of Irlen filters dramatically changes brain activity for the better in individuals suffering with Irlen Syndrome."

Dr. Jeff Lewine, who among many other titles after his name happens to be professor of translational neuroscience and who, interestingly enough, originally was a skeptic and set out and designed his studies in order to disprove the existence of the Irlen phenomenon, writes in his letter, much to my surprise:

> Using magnetoencephalography and subsequently functional MRI, I have found that the brains of children and adults diagnosed with Irlen Syndrome show aberrant organization with hyper-excitability of brain area V5/MT.

That's the visual cortex.

> When the correct glasses are put on, this hyper-excitability is resolved.

This phenomenon that Dr. Lewine is describing can actually be seen on page 17 of your presentation document, where we have a SPECT scan image that's provided by the Amen Clinics showing the dramatic change in brain function when an individual is wearing their optimal colour. The image on I believe it's the left side of the screen is of an individual when they're not using colour. On the right side it is of the individual wearing or using their optimal colour. What this image so nicely shows is: those white areas you see on the screen are considered hot or overactive parts of the brain, and when the individual with Irlen syndrome is utilizing their optimal colour, those areas calm down, and the brain function normalizes. This is especially true in the visual cortex.

Probably what's most important is that these anatomical changes correspond . . .

Ms Kubinec: Are we still in conference? I think maybe we somehow got disconnected, so I'm just going to phone back in.

The Chair: All right. I'm sorry. We had a little technical hiccup, but it looks like they can hear now, so please carry on. Sorry for the interruption.

Dr. Tosta: Okay. No problem. I'll continue.

What I was saying is that these changes that you see in the brain correspond directly to reports from the individuals about changes that they're seeing on the page or in their visual field and also how they're feeling, so a reduction in physical symptoms that they're experiencing.

Now, we know that several of the organizations that spoke here today in opposition to Bill 204 hold the position that research on Irlen's is inconclusive or lacking, and we think it is paramount for you, the committee, to understand the documents that these organizations and individuals are basing their position upon. In most cases the idea that research is inconclusive is based upon a secondary review of research that was published in the early 1990s.

Many have referred to a joint statement that was released in 2009 by the American Academy of Ophthalmology and their colleagues, where they concluded that the scientific evidence didn't support Irlen's. What the committee needs to know about that 2009 position paper is that in it the AAO does not reference any studies published after 2005. Instead, as you can see on the screen, they are referring almost entirely to research that was published prior to 1996, research that is almost 20 years old and in some cases more than 20 years old.

This 2009 document omits 27 studies published after 1995 that show the benefits of colour for individuals with Irlen syndrome. What is it leaving out? It has selectively left out all of the brain and biochemical research and a majority of the placebo-controlled studies that have been conducted in the last decade. Our friend earlier mentioned that document, and it should be a reliable document. If you actually read the document and you look at the sources that they're citing, the research that they're citing is very old. We've listed the 27 omitted studies for you for your reference.

We also know that opponents of Bill 204 in some cases have referred to studies by Ritchie and colleagues that were published more recently and that failed to find positive effect from Irlen overlays. We would like the committee to know that individuals with expertise in statistics, research methods, literacy from institutions such as Duke University Medical Center, Georgetown University, the United States Naval Academy, and the University of Colorado have all come forward to refute this research, calling out methodological and statistical errors that have led to misleading and erroneous conclusions in these papers.

4:10

Both of the studies conducted by Ritchie have been faulted for being underpowered, meaning that the number of people in the study was actually too small to detect a positive effect even when it existed. They've also used incorrect comparison groups. They've compared children who have Irlen syndrome to kids who don't have Irlen syndrome, and I know you guys aren't researchers, but that's sort of empirical research 101. You can't be comparing two groups when they're reasonably not the same. Shamefully, in the 2012 paper the authors both ignored positive results that existed, and they removed positive data after the fact without any scientific reason to do so.

So what does this all mean? To put it very simply, it means that that research by Ritchie is seriously flawed, and as a result the conclusions they present are invalid.

Now I'm going to turn it back to Mrs. Irlen to conclude.

Mrs. Irlen: Just some key take-away points for you to remember. Irlen is a subtype of visual processing deficit where coloured overlays are used as an accepted technology or assistive strategy, which is supported by research. The positive studies far outweigh the negative studies, and the negative research papers are many times based on incomplete and inaccurate information. Education is brain based. Your brain controls how you think, how you feel, and how you perform, and you want to have the best possible brain in order to succeed in school and in life. Colour is to the brain as glasses are to the eye.

Parents are your key stakeholders, and the committee has heard from just a small sampling of those who have Irlen themselves and who do not want their children to struggle in school like they did. This bill is really to give a child a future.

Thank you.

The Chair: All right. Thank you very much to both of you.

Mrs. Irlen, you did get the benefit, of course, of being here all afternoon. Dr. Tosta, I don't have any questions at this point from the members, so I'm going to quickly do some introductions around the table so you know who you've been talking to. We'll just start over here to my right.

Mr. Reynolds: Rob Reynolds, Law Clerk for the Legislative Assembly of Alberta.

Ms Zhang: Nancy Zhang, legislative research officer.

Ms Leonard: Sarah Leonard, legal research officer.

Ms Notley: Rachel Notley, MLA, Edmonton-Strathcona.

Mr. Khan: Stephen Khan, MLA, St. Albert.

Mr. Goudreau: Hector Goudreau, MLA, Dunvegan-Central Peace-Notley.

Mrs. Leskiw: Genia Leskiw, MLA, Bonnyville-Cold Lake.

Mrs. Jablonski: Hello, Dr. Tosta. Mary Anne Jablonski, MLA, Red Deer-North.

Ms Cusanelli: Good afternoon. Christine Cusanelli, MLA for Calgary-Currie.

Mrs. Fritz: Great presentation, Dr. Tosta. We heard you well. Yvonne Fritz, Calgary-Cross, MLA.

Dr. Massolin: Hello. Philip Massolin, manager of research services.

Mr. Tyrell: Chris Tyrell, committee operations.

Ms Rempel: Jody Rempel, committee clerk.

The Chair: Dave Quest, MLA for Strathcona-Sherwood Park and chair of this committee.

On the phones, quietly, please.

Ms Kubinec: Maureen Kubinec, MLA, Barrhead-Morinville-Westlock, standing in for MLA Matt Jeneroux.

Mr. Luan: Jason Luan, Calgary-Hawkwood, standing in for Steve Young.

Mrs. Towle: Kerry Towle, MLA, Innisfail-Sylvan Lake.

Mr. Pedersen: Blake Pedersen, MLA, Medicine Hat.

Mr. Wilson: Jeff Wilson, MLA, Calgary-Shaw.

The Chair: Okay. Questions? Mrs. Jablonski. Again, if we could just keep preambles short and to the question, that would be appreciated.

Mrs. Jablonski: Thank you, Mr. Chairman. Thank you very much for taking the time, making the effort and the expense of being here with us today. It's obvious to us how important this is to you and to the children – all the children, the thousands of children, I understand – that you've helped.

Thank you, Dr. Tosta. That was an excellent presentation. I want to also thank you for pointing out that the *Journal of Pediatrics* published two studies which should never have been accepted for publication in the first place but have become the centerpiece against Irlen's. What I wanted to ask is: if coloured overlays are accepted and being used in so many countries around the world, why aren't our children being given the opportunity here in Alberta? Do you know why that might be?

Mrs. Irlen: Absolutely no idea, and it's probably a key question. Why is it accepted in key countries around the world yet not here?

Mrs. Jablonski: Is it your hope that by being here to present that, we'll help some of our people to have open minds and understand what Irlen's is about?

Mrs. Irlen: That's why I took the time to come here personally, to show how critical and how important it is, that there are millions of children now world-wide that are using coloured overlays, and that it's a very simple, easy, low-cost technology.

Mrs. Jablonski: My colleague here just whispered: how much are the overlays?

Mrs. Irlen: Oh, a couple of dollars. Seriously.

Mrs. Jablonski: Thank you very much, Helen and Dr. Tosta.

The Chair: I have no other speakers on my list right now. In that case, thank you so much for coming all the way from Long Beach to see us today. We very much appreciate that. Thank you to Dr. Tosta for joining us through the video conference.

Dr. Tosta: My pleasure.

Mrs. Leskiw: Can I just ask a question since you guys came all this way? I can't understand why all the negativity to it. I mean, you would think that people would embrace anything that would help a child. What have you found about why optometrists and ophthalmologists and all these people are so darn against helping these kids?

Mrs. Irlen: I think it's because we're stepping on people's toes professionally. If you look at the visual system, the visual system starts with the eye but goes to the brain, and any problems along the way have similar symptoms, so the optometrists feel that we're in their territory treating their problems. Yet the optometrist who initially – there are two main optometrists, one from the U.K., which is Bruce Evans, and the other from the U.S., which is Scheiman, who came out and said: yes, this is really a binocular problem, et cetera, et cetera. They totally changed their position even though they published research. Well, Bruce Evans in the last 10 years has incorporated colour into his practice and goes around and trains both optometrists and educators in the importance of colour. It doesn't overlap, okay? The same thing with Scheiman. He's totally changed his position.

Mrs. Leskiw: Would you say that an analogy could be how some doctors feel about chiropractors or, you know, that animosity between the different types of professionals? You know, natural healers versus physicians, optometrists versus ophthalmologists. You get that kind of friction sometimes where there really shouldn't be.

Mrs. Irlen: Well, I think it's a combination, and that's one important issue. Two, people have a difficult time accepting something new. Educational systems move very slowly. I was told it takes 30 years to get something accepted. We're at 30 years plus, so it's about time.

In addition, the majority of the population does not have Irlen syndrome, so the symptoms, to them, make absolutely no sense, and then they can't believe in it.

The Chair: All right.

Mr. Khan: Mrs. Irlen, thank you again for your presentation. Dr. Tosta, an outstanding presentation. It's very much appreciated the long distance that you've come to be here today. This is almost a supplemental question to that of my colleague Mrs. Leskiw. You've spoken to perhaps a professional tension between those in the Irlen's world and those in the medical profession and the ophthalmology profession. I'm asking you: is there something, in your opinion, perhaps that might bridge that gap or something we could do that might help bridge that gap?

Mrs. Irlen: That's an excellent question. I think part of it is the fact that we need to truly separate ourselves, even though the symptoms seem similar, to make sure that people understand that we know this is a piece of the puzzle, that the people who are identifying this – you know, we're not diagnosing a medical condition; we're identifying an issue – do differential diagnoses. That's why the people who are trained are able to do differential diagnoses.

4:20

I'd like to point out that 30 years ago, when I first started doing this research with adults, I was doing it with adults who were bright enough to make it to a four-year university but still struggling. I had been a school psychologist for the past 15 years and was very used to psychoeducational testing on every child that we saw and was very aware that the testing that we were doing was missing something, that we were not identifying all of the children who were still struggling in school.

When I had the opportunity to establish the program for adults with learning disabilities at a university level, I established a research component as well to look at these adults and say: what are the issues we're not identifying? If we stay with and just ask the same questions that we do all the time in terms of psychoeducational evaluations, we're only going to be helping a certain per cent of the population. What are the issues that will continue with an individual for a lifetime that we're not presently identifying or addressing? This was one of 12 issues that popped out, okay?

The second thing that we did – because my assumption was that, well, gee; these people just don't have a language to describe what is happening to them – was that now we gave them the awareness of the language so that they could then go to a professional. And there was some professional group out there that had the technology to help them. We took nine months, and we had a board consisting of ophthalmologists, optometrists, developmental optometrists, psychologists, neurologists, and educators, and these 35 adults went to each one of these professions, explained their problems, and whatever they recommended was done, right? At the end of the nine months, I ended up with 35 adults complaining of the same problems and the same issues. They still had them regardless of any intervention that had been tried.

It was only then that I turned around and said that we need to work for something new. I had assumed that this was just going to be part of the protocol that some professional out there was going to be able to address.

Thank you.

Mr. Khan: Thank you.

Mrs. Jablonski: This question – I hope you don't mind, Helen – is for Dr. Tosta. Dr. Tosta, you reviewed much of the research in this area of study, and we know that Evans and Scheiman were some of the key optometric researchers. I want to know if researchers Evans and Scheiman still feel that coloured overlays cannot help reading as they stated originally.

Dr. Tosta: Well, I think that Helen actually mentioned already that both of those professionals have changed their tune and are currently utilizing colour in their personal practices. So the answer is that, no, they don't hold the same position; they're currently proponents of the use of colour.

Mrs. Jablonski: Thank you very much. Just let me be clear, then. They originally didn't think colour was helpful, that it was not a piece of the puzzle and couldn't solve anything, and now they've reversed their position. Is that correct?

Dr. Tosta: Correct. They were two of the original folks that came out and said, just as we heard earlier in the presentations today: "You know, it's just an eye problem. It's just an optometric problem. If you correct their eye problems, all these problems are going to go away." Subsequently, they realized that that actually wasn't the case. As Judy Pool and her colleague mentioned earlier, when it comes to Irlen's, it's very important to us as Irlen professionals to take care of those eye problems before you start addressing Irlen's, because Irlen's is not going to fix an eye problem if they have an eye problem. The optometrist and corrective lenses need to do that. This will not fix that. Lots of our clients have glasses that have a prescription, or they wear their prescription and they're using colour. That is very, very common. As I mentioned in the presentation, there is research out there. I think it is about five studies out there that have shown that these optometric issues are not the same as Irlen's.

Mrs. Jablonski: Thank you very much.

Dr. Tosta: Uh-huh.

The Chair: All right.

Ms Cusanelli.

Ms Cusanelli: Thank you, Chair. My question, I guess, is once again around the role of the teacher. Having come from an educational background myself, you know, I was often as a principal very protective about what sorts of roles and responsibilities were important to make sure that my teachers followed through on, so that's where my issue is with this particular act. My belief is that the actual recognition of the symptoms of Irlen syndrome shouldn't really be on the laps or the shoulders or part of the responsibility of what the teacher should be doing in the classroom.

I'm wondering: what is your belief about the role of the teacher as it relates to being able to appropriately identify this kind of syndrome without, perhaps, background, without the professional designation or certification?

I want to also say thank you so much for being here. As an educator I think parents, when they sit with us, often have a question, and we don't always have the answer, but I do believe that Irlen syndrome testing is something that – and that's why I have a lot of respect for your being here – if we raise some of the awareness within our own province about it, gives parents yet another option to at least look at. At the end of the day does it really matter if, you know, certain bodies believe that this research is accurate versus not? If it works for an individual, that's kind of all that matters.

Mrs. Irlen: You can make research say anything you want it to say, by the way.

You have to understand that, yes, I got to create this whole thing, right? As an educator and a school psychologist I had strong feelings about creating a model that would fit into the educational system. I truly believe in the fact that it does belong in the educational system and that we do have various models in many countries, including the U.S., where we have teachers who then are trained as screeners so that they can identify those students in the schools and just provide the overlay, which means it's a couple of dollars to help a student that would have stayed in special education or needed private tutoring or on and on in terms of most of them needing readers and extended time, those kinds of things.

When we're setting this in terms of saying that we want educators to at least be aware and suggest it, they're not identifying anything. They're suggesting. This problem is hereditary, okay? Every time we identify a child, we also identify either mother, dad, or both. I have found that with the screening instruments, just even the screening questionnaires that kind of identify whether you may be a candidate for this or not, parents go in starting to look at the questions for their child and end up answering the questions for both themselves and their child. I end up with two of those. It doesn't take brain science to just identify whether this is a possibility. We're talking about a possibility. We're talking about the fact that if the school system doesn't do it, nobody is going to do it. I'd say that 80 to 90 per cent of the individuals that we see come to us because they are referred not by professionals but by other parents who have been helped or their child has been helped. They discuss the symptoms and say: "Yeah, that is my child. My child has those same symptoms."

It's got to be somewhere, and it's got to be somewhere professional where we create that awareness, and I am totally committed to the educational system as being that vehicle for spreading the word and just creating the knowledge.

The Chair: Great. Thank you, Mrs. Irlen. I have to stop you there, but thank you so much again for your presentation, and thank you to all the presenters that were able to join us this afternoon. Members of the public, again, thanks for your interest and for being here with us. You're all welcome to stay.

We have a couple of business items that we have to deal with fairly quickly because I can tell that I'm going to start losing members any minute, so we're going to move on to those.
Thank you again to everybody here.

Mrs. Irlen: Thank you very much.
Dr. Tosta, thank you.

Dr. Tosta: Thank you.

The Chair: All right. Agenda item 5, next steps. Now, we've had 70 written submissions, six stakeholder presentations today, plus a presentation from our bill's sponsor, so we've had a great deal of information submitted. I'd suggest that we meet again in early October for deliberations and to consider this further and then give our committee staff some direction with respect to drafting a report and developing some recommendations on Bill 204. Any questions on where we're going next? We'll make sure that the members are all polled and try and come up with a date that is convenient for as many members as possible.

4:30

All right. Then there is one other item, item 6. We did have a delayed submission. We're not sure why. It was actually submitted on July 5, before the deadline that we'd established for submissions, yet it sat in an inbox until August 29.

Ms Notley: I move that
we accept it.

The Chair: Excellent. Any discussion? All in favour? Great. We will take that submission.
The next meeting is at the call of the chair. We just discussed that. We'll try to make that convenient for as many members as possible.
I need a motion to adjourn. Ms Cusanelli. All in favour? We are adjourned. Thank you very much, everyone.

[The committee adjourned at 4:31 p.m.]

Published under the Authority of the Speaker
of the Legislative Assembly of Alberta