

2009 SENATE HUMAN SERVICES

SB 2412

2009 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. SB 2412

Senate Human Services Committee

Check here for Conference Committee

Hearing Date: 2-03-09

Recorder Job Number: 8454, 8533, 8535

Committee Clerk Signature

Mary K. Morrison

Minutes:

Senator J. Lee opened the hearing on SB 8454 to provide an appropriation to the state department of health for providing a grant to the ND fetal alcohol syndrome center.

Senator Ray Holberg (District # 17) was a sponsor and introduced SB 2412 as a policy question first. If the committee determines this is something that the state should spend its money on then it's up to the Appropriations Committee to see if they can find the money.

Larry Burd (Professor of Pediatrics at the University of North Dakota School of Medicine and Health Sciences) spoke in support of SB 2412. See attachment #1.

Senator Heckaman asked what the numbers on the map on page 2 represented.

Dr. Burd replied that it was a map of the current cases where they were living the last time contact was made.

Senator J. Lee asked how they would connect with a family who had a child with fetal alcohol syndrome.

Dr. Burd said they are referred – about 1/3 from physicians, 1/3 programs in schools or social services, and 1/3 from parents.

Senator J. Lee asked if the parents would be the adoptive parents.

Dr. Burd said only about 10% of children with FAS live with their biological parents. Most are in foster care or residential care or adopted.

Senator Dever asked how the appropriation would be utilized.

Dr. Burd replied that they need staff for education and training.

Senator Erbele asked about the mortality rate and if there are current figures.

Dr. Burd said three papers have been published on mortality rate and FAS disorders. The mortality risk for children has increased fourfold if they have FAS disorder. It accounts for about 1/7 of mortality in ND after 1 month of age. He then addressed causes of death.

Senator Dever - if the problem is multiple births by the same mother is there any kind of intervention when the first child is born.

Dr. Burd said this really is the problem. Right now in the system it isn't anybody's task to find that mother after she leaves the hospital and try to get her into treatment.

Senator Dever suggested that these mothers also don't present themselves for prenatal care.

Dr. Burd – They tend to show up for one or two prenatal visits.

Senator Dever stated that several sessions ago some language was put into code about intervention when the doctor suspects that there is alcohol involvement. Does that play out in the real world?

Dr. Burd said it doesn't in the moms they see. He addressed the misconception that this is a minority problem. Some of the women they see who have the most affected children are white women living in the four largest cities.

The larger concentration of this problem in the urban areas versus the rural areas and possible reasons was discussed.

Rodell Ottum and his wife Cheryl with son Austin and adopted son Sterling testified in support of SB 2412. Attachment #2.

There was no opposing testimony.

Kim Senn (Director of the Division of Family Health ND Department of Health) spoke about what is currently going on to help families with FAS disorders in their lives. She said what Dr. Burd is doing at UND is the major effort going on in ND. Providing funding to him will help increase those efforts. Partnering with Dr. Burd and the education that would be provided to all the health care professionals working in all the different areas would be critical to help prevent FAS.

Senator J. Lee asked Dr. Burd if he needed 1FTE.

Dr. Burd replied that he had 3 people slated to do this work and went on to explain the training they do and how they do it. A federal grant had been used but when the grant ran out the efforts stopped. They need 3FTE.

There was discussion on what wouldn't be able to happen if the full funding wasn't there. They would prioritize the training. The number one training priority for them would be to reach the prenatal care providers and show them how to ask about prenatal alcohol use and do something about it.

Senator J. Lee asked if there was any direct service provision that would be available for the families.

Dr. Burd said they have a multidisciplinary team -- (1) try to figure out what kind of help is needed. (2) help with therapy needed (intervention) and (3) help people understand the long term outcomes.

Cheryl Ottum (PATH of ND) talked about the problems associated with FAS disorders and wanted to emphasize the importance of needing more resources.

Kim Jacobson (Trail County Social Services) urged support of SB 2412.

The public hearing of SB 2412 was closed.

Job #8533 (meter 00:00 to 03:35)

Senator Heckaman suggested that a report be given back on how the funds were used so there is some accountability. It would give information on how many FTE's they were able to hire and how many contacts they were able to make.

Senator J. Lee – to the appropriate legislative council committee?

The committee thought an accountability report would be a good way to see how the Fetal Alcohol Syndrome Center used the appropriation.

Job #8534

Senator Dever moved to amend calling for a report to legislative council before Sept. 1, 2010.

Seconded by **Senator Heckaman**.

Roll call vote 5-0-1 (Senator Marcellais) **Amendment adopted.**

Senator Dever moved a **Do Pass as Amended and rerefer to Appropriations.**

Seconded by **Senator Erbele**.

Roll call vote 5-0-1 (Senator Maracellais). **Motion carried.**

Carrier is **Senator Pomeroy**.

JB
2-4-9

PROPOSED AMENDMENTS TO SENATE BILL NO. 2412

Page 1, line 2, after "center" insert "; and to provide a report to the legislative council"

Page 1, after line 8, insert:

"SECTION 2. ACCOUNTABILITY REPORT TO LEGISLATIVE COUNCIL.
The North Dakota fetal alcohol syndrome center shall provide an accountability report with respect to the use of funds granted under section 1 of this Act to the legislative council before September 1, 2010."

Renumber accordingly

Date: 2-3-09

Roll Call Vote #: 1

2009 SENATE STANDING COMMITTEE ROLL CALL VOTES

BILL/RESOLUTION NO. SB 2412

Senate Human Services Committee

Check here for Conference Committee

Legislative Council Amendment Number Report by 9-1-2010

Action Taken Do Pass Do Not Pass Amended Rerefer to Appropriations
 Adopt Amendment Reconsider

Motion Made By Sen. Dever Seconded By Sen. Heckaman

| Senators | Yes | No | Senators | Yes | No |
|--------------------------------|-----|----|----------------------------|-----|----|
| Senator Judy Lee, Chairman | ✓ | | Senator Joan Heckaman | ✓ | |
| Senator Robert Erbele, V.Chair | ✓ | | Senator Richard Marcellais | | |
| Senator Dick Dever | ✓ | | Senator Jim Pomeroy | ✓ | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |

Total (Yes) 5 No 0

Absent 1

Floor Assignment _____

If the vote is on an amendment, briefly indicate intent:

Date: 2-3-09

Roll Call Vote #: 2

2009 SENATE STANDING COMMITTEE ROLL CALL VOTES

BILL/RESOLUTION NO. SB2412

Senate Human Services Committee

Check here for Conference Committee

Legislative Council Amendment Number 90835.0201 Title 0300

Action Taken Do Pass Do Not Pass Amended Rerefer to Appropriations
 Adopt Amendment Reconsider

Motion Made By Sen. Dever Seconded By Sen. Erbele

| Senators | Yes | No | Senators | Yes | No |
|--------------------------------|-----|----|----------------------------|-----|----|
| Senator Judy Lee, Chairman | ✓ | | Senator Joan Heckaman | ✓ | |
| Senator Robert Erbele, V.Chair | ✓ | | Senator Richard Marcellais | | |
| Senator Dick Dever | ✓ | | Senator Jim Pomeroy | ✓ | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |

Total (Yes) 5 No 0

Absent 1

Floor Assignment Senator Pomeroy

If the vote is on an amendment, briefly indicate intent:

REPORT OF STANDING COMMITTEE

SB 2412: Human Services Committee (Sen. J. Lee, Chairman) recommends AMENDMENTS AS FOLLOWS and when so amended, recommends DO PASS and BE REREFERRED to the Appropriations Committee (5 YEAS, 0 NAYS, 1 ABSENT AND NOT VOTING). SB 2412 was placed on the Sixth order on the calendar.

Page 1, line 2, after "center" insert "; and to provide a report to the legislative council"

Page 1, after line 8, insert:

"SECTION 2. ACCOUNTABILITY REPORT TO LEGISLATIVE COUNCIL.

The North Dakota fetal alcohol syndrome center shall provide an accountability report with respect to the use of funds granted under section 1 of this Act to the legislative council before September 1, 2010."

Renumber accordingly

2009 SENATE APPROPRIATIONS

SB 2412

2009 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. SB 2412

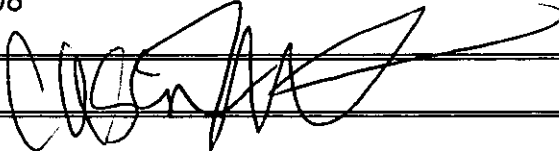
Senate Appropriations Committee

Check here for Conference Committee

Hearing Date: February 11, 2009

Recorder Job Number: 9208

Committee Clerk Signature



Minutes:

V. Chair Sen. Grindberg called the committee hearing SB 2412 in order to provide an appropriation to the state department of health for providing a grant to the North Dakota fetal Alcohol Syndrome center.

Larry Burd, Professor of Pediatrics at the UND School of Medicine and Health Sciences, testified in favor of the bill. See attached testimony, attachment #1.

Sen. Robinson- what are the number of cases in the state with FASD?

Larry- the issue of FASD is a very difficult one cause it is very hard to diagnose, the problem is this is that nearly all of these kids are in foster care. The severity of alcoholism with their parents is so great that it is very uncommon for them to be living with their parents. So they get taken out of the home moved around and eventually someone brings them in for an evaluation but we have no way of going back and demonstrating that there was actual alcohol abuse during pregnancy and that is a key to diagnosis of this disorder. So we are unable to diagnose it so right now we are thinking that in the US the prevalence of FASD is about 1%, 1 out of every 100 newborns around 70 a year in ND.

Sen. Wardner- could you explain the color code and the acronyms on your one chart in your attachment?

Larry Burd went over the chart in his attachment with the committee.

Sen. Christmann- We all think this is a very sad thing but what if this money going to do about it?

Larry Burd- I am very cynical about prevention efforts, first we spend about 7.5 million dollars over 15 years figuring out how to do this. We have tried many different prevention efforts through knowledge and so on. Right now are mostly focused on women that have a affected child and try to work with her, in 5 years of doing this we prevent 1/3 of new cases. So we are here asking for money to implement a project that we have studied using federal money.

Sen. Robinson- Do you hear from adoptive parents that suspect child has FASD. Do you have resources to help them with babies affected?

Larry- of the people that I see the two problems that are the most common are fetal alcohol spectrum disorders and autism. (Went over second page of his chart in his attachment with the committee)

Sen. Mathern- one of my concerns is who is going to take over after you when you are literally the only person in ND that knows how to do diagnosis?

Larry- we are making good progress, every year we use federal funding to pay 2 medical students to spend 6 weeks between their first and second year of medical school to spend time with us. We have been doing this a long time and we are coming up with a group of physicians who are much better able to manage the problem once it is diagnosed.

No opposition to the bill.

Sen. Mathern- I was involved with the committee that kind of helped find what it is what the legislature might be open to, in some ways I am frustrated that they are not literally doing more because research is so strong and it is clear that it is important that we are working in this area. I hope that we can support this.

Sen. Kilzer- I would just like to know a little bit about the history of the funding? I would like to see something in writing.

Larry Burd- can you fill me in a little bit more on what would be helpful for you?

Sen. Kilzer- I just have the bill in front of me but I don't have the history of what we have done in the past and where the source is of where the finances are.

Larry Burd- I will try to make that available tomorrow.

Chairman Sen. Holmberg- we will find out, you can send it by email and then I can forward it to the committee.

Senator Krebsbach I always heard of it called Fetal Alcohol Syndrome, when did that change and does anyone have any idea of when that came about?

Sen. Mathern- it is actually changing every 2 years as people become more aware of this and there are more studies being done and they are just coming up with new terms.

Sen. Kilzer- there are two different degrees of severity.

Chairman Sen. Holmberg closed the hearing on SB 2412.

2358

Bridge the dental gap

Whatever the subcommittee would like. This is not a function of state government.

Senator Fischer can't support either bill SB 2356 and 2358.

Senator Mathern what if we amend this.

Senator Fischer said he understood the need.

Senator Kilzer I much prefer the dental loan payback then getting into the equipment business. I think we should put a do not pass. **Senator Kilzer** yes, **Senator Fischer** yes, **Senator Mathern** no. The committee recommends a DO NOT PASS ON SB 2356.

2358

Was this in the governor's budget and not in optional package?

Arvy said it was not.

Senator Mathern: Gives money to students of dentistry for 3 years and if they practice for three years their loan payment is taken care of.

Senator Fischer recommends do pass and all three agree on a Do Pass for 2358.

2412 the bill on Fetal Alcohol Syndrome was heard today in committee.

Senator Fischer we asked for legislative council to get information for us.

Senator Kilzer I think we should see the results of the history of it.

Maybe we can have a quick meeting after we get those emails.

Senator Kilzer any other things we should know about.

Senator Fischer SB 2063 passed on the floor today. That never came here. It was rereferred to appropriations today.

2009 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. 2412


Senate Appropriations Committee

Check here for Conference Committee

Hearing Date: 02-17-09

Recorder Job Number: 9629

Committee Clerk Signature



Minutes:

Chairman Holmberg opened discussion on SB 2412 (19.18) indicating this is the fetal alcohol syndrome bill.

Senator Fischer Moved DO PASS on SB 2412; seconded by Senator Mathern. A roll call vote was taken resulting in DO PASS on SB 2412 with 14 yes, 0 no, 0 absent. The bill will be carried by Senator Pomeroy in Human Services (20.55).

Chairman Holmberg closed the hearing on SB 2412.

Date: 2/17/09
 Roll Call Vote #: 1

2009 SENATE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2412

Senate _____ Committee _____

Check here for Conference Committee

Legislative Council Amendment Number _____

Action Taken Do Pass Do Not Pass Amended

Motion Made By Fischer Seconded By Mather

| Representatives | Yes | No | Representatives | Yes | No |
|--------------------|-----|----|------------------|-----|----|
| Senator Wardner | ✓ | | Senator Robinson | ✓ | |
| Senator Fischer | ✓ | | Senator Lindaas | ✓ | |
| V. Chair Bowman | ✓ | | Senator Warner | ✓ | |
| Senator Krebsbach | ✓ | | Senator Krauter | ✓ | |
| Senator Christmann | ✓ | | Senator Seymour | ✓ | |
| Chairman Holmberg | ✓ | | Senator Mather | ✓ | |
| Senator Kilzer | ✓ | | | | |
| V. Chair Grindberg | ✓ | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |

Total Yes 14 No 0

Absent 0

Floor Assignment Human Services

If the vote is on an amendment, briefly indicate intent:

Jim Pomeroy

REPORT OF STANDING COMMITTEE (410)
February 17, 2009 10:53 a.m.

Module No: SR-31-3073
Carrier: Pomeroy
Insert LC: . Title: .

REPORT OF STANDING COMMITTEE

SB 2412, as engrossed: Appropriations Committee (Sen. Holmberg, Chairman)
recommends **DO PASS** (14 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING).
Engrossed SB 2412 was placed on the Eleventh order on the calendar.

2009 HOUSE HUMAN SERVICES

SB 2412

2009 HOUSE STANDING COMMITTEE MINUTES

Bill/Resolution No. 2412

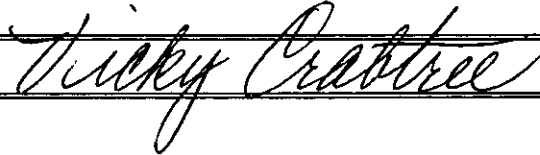
House Human Services Committee

Check here for Conference Committee

Hearing Date: March 10, 2009

Recorder Job Number: 10559

Committee Clerk Signature



Minutes:

Chairman Weisz opened the hearing on SB 2412.

Sen. Holmberg sponsored and introduced the bill: See Testimony #1.

Rep. Porter: You brought up the public service announcements and the posters and TV ads

for fetal alcohol syndrome. Is that money currently in the Health Dept.'s budget to do those?

Are we part of that and could we use some of that money to be refocused to this center to get more bang for our buck?

Sen. Holmberg: The money your thinking about might be separate and (inaudible). I do know that in some areas it appears research indicates that kind of PSA stuff might work. Weather it is tobacco saturation or some other programs. Research over 14 years indicates that it does not work in ND to have that kind of signage. It does not grab the attention of the handful of people you really have to work with. If Appropriations can move that money over, they will find a way.

Chairman Weisz: We do have the testimony from Dr. Burd and will try and arrange a conference call with him.

Sen. Holmberg: A lot of these kids are adopted. These children have many health problems.

Rep. Uglem: I assume all these mothers are addicted to alcohol. Is birth control an answer?

Sen. Holmberg: They are out of control. Alcohol exposure is more devastating to the baby than meth.

NO OPPOSITION.

2009 HOUSE STANDING COMMITTEE MINUTES

Bill/Resolution No. 2412

House Human Services Committee

Check here for Conference Committee

Hearing Date: March 11, 2009

Recorder Job Number: 10764

Committee Clerk Signature

Wicky Crabtree

Minutes:

Chairman Weisz: We are going to have a conference call with Dr. Burd about SB 2412. Dr. Burd this is Rep. Weisz in the House Human Services Committee and we are currently taking up SB 2412, the fetal alcohol bill and if you would like to make a few remarks you are welcome to and the and I will ask any questions the committee may have for you and you can respond.

Dr. Burd: We have used the national institute for health spending to spread the how to do prevention in fetal alcohol spectrum disorders. We spent many years doing that and have arrived at a strategy which is effective. We have tested in ND so we know that it works. It deals with those three key areas; of identifying alcohol use in prenatal care, trying to help providers understand the drug use usually is accompanied by alcohol use in especially pregnant women and it is very important for people to look at how to prevent recurrence of these FAS children and families. As I note it is not a lot of women having a few children with FAS, it is a few women who tend to have fairly large numbers of children and I've demonstrated in that pedigree how that looks in a family from ND. And the last item is the graph down there and for this graph we used the data from the ND medical assistance looking at the cost savings just from health care. Does it deal with special education costs or

intervention (inaudible). Just health care costs. As you can see it is a very beneficial prevention strategy from the standpoint of saving money in medical assistance.

Chairman Weisz: Your study obviously showed a few women having a many children, so how do you address that? What is the prevention that is going to change that, getting to those few women that are having multiple children with fetal alcohol?

Dr. Burd: We would focus on that by these three key steps: 1) we have developed a brief set of tools that we hand out to pre-natal care providers across the state. We have to do this often because people change, they lose them, they forget about them and so we need to repeat that, 2) is that we need to do a lot of training to help people understand that are current strategy for identifying women who (inaudible) aren't that successful, but we can change that. It actually takes less time from the nursing and physicians who are doing this, rather than more time, and 3) deals with your question. When we diagnose these children with FAS what we have done in the past is just written a report and sent it out, but now we are trying to go back to these communities, and we've tested this on two reservation communities here in Grand Forks, to identify these moms and try to get them into treatment. We are not always successful, but we do think we can prevent one-third of the cases.

Rep. Porter: When you look at the budget of \$184,000 year for the next two years, we have a lot of that going to staff and then travel. What do you see the staff job in this position actually doing?

Dr. Burd: They will visit every female care provider in ND and provide them with a little training and materials. They will visit the providers, hospitals and WIC clinics. WIC is a very useful place to look for moms at high risk. We will have one person who will follow-up on these women who have children FAS and trying to get them into treatment.

Rep. Porter: In the bill it says you are to report back to the legislature by December 1, 2010. Is that going to be enough time to extract the data of what you are doing and see where you are actually going to have the one-third reduction in fetal alcohol syndrome in ND?

Dr. Burd: No. It will take longer than that. What we can do report to you how successful we have been at doing the contacting, like the prenatal care providers and if you would like we can get an evaluation from them on their view of the training.

Rep. Porter: How long do you see this particular going then to get the results that you are projection?

Dr. Burd: I think it would have to be an on-going project for quite some time because alcohol use among pregnant women actually has been rising over the past six years and I don' see any way we can instill a permanent fix on a short term basis for a problem like this. Much of our focus is on individual providers and individual women.

Rep. Frantsvog: You talked about the three effective strategies and you identified the third key is prevention of recurrence. Is that mainly achieved through counseling? How do you get to these people and how do you do the third key?

Dr. Burd: The strategy we used and tested was to find children who had the diagnosis and I think that is key because if we spread our efforts out over just children who might have the diagnosis, there is far too many of them. Then when Dr. (inaudible), the geneticist sees them in one of these clinics we do around the state, then we try to follow-up some of those women and get them into treatment. I wouldn't minimum in any way for you the difficulty we have with that. Most of these are alcoholic women who have a lot of life struggles and so two-thirds of the time we are not successful, but one-third we have been and turns out to be the on-third is more than enough to cover the projective costs for these in the out years as you can see.

Rep. Frantsvog: So, the third key is not counseling, that is getting them to take the cure?

Dr. Burd: Most of these women require treatment. I did find women in pre-natal care who have alcohol use problems. Counseling (inaudible) is very successful. If we could get pre-natal care providers to do a better job of that, that will probably have more affect over the long term than these other strategies. It is very time consuming to train that many people and they keep changing so we have to keep going back and doing it over and over again. But, women who have a drinking problem and have one or two children with FASD have not been that successful with counseling and is not that effective . We concentrate our efforts in getting them into a treatment center. It is kind of like cigarette smoking, it might take several times before you can quit.

Rep. Hofstad: Since treatment is an important part of the strategy, could you expound on the cooperative efforts you have with treatment centers across the state? Is that part of your focus and emphasis?

Dr. Burd: Many of these treatment centers have received training. We spent a good deal of time with Perry Wicks down at the state treatment plan in Jamestown. They have on-going meetings we attend some of those meetings and provides an update of this problem and how to deal with it. As you can see from this graph of a family, many of the women who have children with FASD are themselves affected. One of the things we try to point out to people is that if you are going to be successful, you have to adapt your treatment for these women who have learning disabilities and other problems, so the treatment has to be modified in order to be most effective for them.

Rep. Conrad: Are there particular centers in ND that are good at this working with these gals?

Dr. Burd: The treatment center of Jamestown, I think has been impressively successful at dealing with women who have fetal alcohol syndrome and in modifying their treatment for this population. We have two centers now, don't know if they are privately or state funded, who

deal just with women and have managed to overcome some of the barriers to treatment. Many of these women have children and some are in foster care, but they are very sensitive to things that might complicate their relationship with social services. So we try to help them identify a center that we think would best meet their needs. I've been most impressed by this program at the state hospital.

Rep. Frantsvog: Could you give us a comparison of what the current staff is at the center that is in place now and how it would change if you were funded with this \$369,000.

Dr. Burd: We are currently at 85%-90% funded by federal money. We have four people working at Mercy Hospital on a research project there called Safe Passages. There are three of us here. We receive \$19,300 a year in state funding and the rest is supported by federal money. As you are probably aware, the national institute of health does support demonstration projects, but they don't support the long term implementation of these projects once they have been shown to work. Our efforts here are going to depend on this funding because we don't have a way as it currently stands to continue it without that funding. There are seven people here now if that is helpful.

Rep. Porter: Wondering if your findings have been published or implemented in other state yet?

Dr. Burd: I've been to almost every state and 13 different countries talking about this problem. We have large projects running in China, Brazil, Tasmania and getting ready to start one in Argentina and one in Australia. I think there are three states I have not been to, to talk about fetal alcohol syndrome. Most of those talks are supported by the state or the rest of them were supported by the national institute of health.

Rep. Porter: Any of those areas where implementation has taken place have they started to see results.

Dr. Burd: There are two states in the U.S. that are as far along with fetal alcohol syndrome as ND is and they are Minnesota and Washington. The rest of the states are many, many years behind us. In Washington they have a slightly different model focused on women with severe substance abuse and they have as good or better results than we do. Much of the two programs overlap. They just have a much greater focus on individualized treatment and the (inaudible) entity. And here that is not feasible because we are too rural.

Chairman Weisz: Doctor thank you very much for being able to get on this conference call and sorry you weren't able to make it because of the weather. We will be making a decision this afternoon on the bill and will let you know what happens.

Dr. Burd: Thank you.

Rep. Porter: I think that as we look at other projects of implementation this particular project is one of those that has a slight investment into this problem and that is a pretty big return over time. It will take more than one biennium to see if it works, but they will be staying in touch with us as they move forward. Sometimes you can reduce the funding because these networks can take over themselves after awhile. I think it is a worthy project to try moving forward with.

Rep. Porter: Motion Do Pass and Re-refer to Appropriations.

Rep. Conrad: Second.

Chairman Weisz: I wish I would have asked him what was the reason that we are now seeing an increase and if it had been declining in general with education efforts.

Rep. Frantsvog: I can only state I felt better about the project before I talked to the Doctor then I do now, but I will support the do pass. One of the things I hope is that the Dept. of Health would request a report because I would guess we will be asked for money again next session.

Rep. Porter: That is in Section 2 of the bill.

Chairman Weisz: The engrossed version has that provision in there.

Rep. Conrad: I've known Dr. Burd for many years. He will be so accountable, he is very thorough and he is a gem we have in our midst.

Roll Call Vote for Do Pass: 11 yes, 0 no, 2 absent, Rep. Damschen and Potter.

MOTION CARRIED DO PASS.

BILL CARRIER: Rep. Holman

Date: 3-11-09

Roll Call Vote #:

2009 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2412

House HUMAN SERVICES Committee

Check here for Conference Committee

Legislative Council Amendment Number _____

Action Taken Do Pass Do Not Pass Amended

Motion Made By Rep. PORTER Seconded By Rep. CONRAD

| Representatives | Yes | No | Representatives | Yes | No |
|---------------------------|-----|----|-------------------------|-----|----|
| CHAIRMAN ROBIN WEISZ | ✓ | | REP. TOM CONKLIN | ✓ | |
| VICE-CHAIR VONNIE PIETSCH | ✓ | | REP. KARI L CONRAD | ✓ | |
| REP. CHUCK DAMSCHEN | A | | REP. RICHARD HOLMAN | ✓ | |
| REP. ROBERT FRANTSVOG | ✓ | | REP. ROBERT KILICHOWSKI | ✓ | |
| REP. CURT HOFSTAD | ✓ | | REP. LOUISE POTTER | A | |
| REP. MICHAEL R. NATHE | ✓ | | | | |
| REP. TODD PORTER | ✓ | | | | |
| REP. GERRY UGLEM | ✓ | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |

Total (Yes) 11 No 0

Absent 2

Bill Carrier _____

If the vote is on an amendment, briefly indicate intent:

*Motion Carried
Do Pass Re-referred
Appropriations*

REPORT OF STANDING COMMITTEE

SB 2412, as engrossed: Human Services Committee (Rep. Welsz, Chairman) recommends **DO PASS** and **BE REREFERRED** to the Appropriations Committee (11 YEAS, 0 NAYS, 2 ABSENT AND NOT VOTING). Engrossed SB 2412 was rereferred to the Appropriations Committee.

2009 HOUSE APPROPRIATIONS

SB 2412

2009 HOUSE STANDING COMMITTEE MINUTES

SB 2412

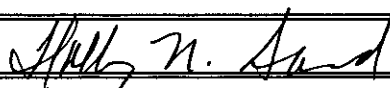
House Appropriations Committee

Check here for Conference Committee

Hearing Date: March 19, 2009

Recorder Job Number: 11292

Committee Clerk Signature



Minutes:

Chm. Svedjan turned the Committee's attention to SB 2412.

Rep. Weisz: SB 2412 deals with Fetal Alcohol Syndrome (FAS) Disorder. Fetal Alcohol Syndrome is irreversible and is caused solely from alcohol consumption during pregnancy.

There is no cure. It is easily preventable if you don't drink. We received a lot of testimony that shows there are many women who have FAS babies that often have multiple births. This bill establishes a preventive service program to work with these women who have been identified as having children with FAS before. After the research and a study, they believe that they can reach 30% of these women. This is strictly alcohol. Alcohol has a much greater effect on a fetus than meth. That's how damaging alcohol can be. It costs about \$2.4 million to care for a FAS child during his or her life. They are asking for \$369,000. They can potentially reach one third of these women. They will focus on those women who have already had a FAS baby to try to get them into treatment or another program.

Chm. Svedjan: Do you have a breakout of the expenditures.

Representative Weisz:

| | |
|------------------------------|-----------|
| Personnel | \$164,950 |
| Travel | \$ 12,500 |
| Printing, Postage, Telephone | \$ 4,900 |

Supplies, prevention materials,

Computer and software \$ 2,800

Rep. Wald: Is this an ongoing program? Is there something in place now?

Rep. Weisz: This is a new program. There is nothing that specifically addresses FAS.

Rep. Wald: Is there money in any other budget?

Rep. Weisz: No, not on the preventive end. Often most of these babies end up in Medicaid, so we end up taking care of them for their whole life.

Chm. Svedjan: This is not the first time we have funded this. HB 1313. It's the most unusual circumstance that I have ever had in the legislature. The bill came to the appropriations committee asking for something like \$150,000 and came out of Appropriations with a Do Not Pass. There was a motion on the floor to strip the money out because we wanted to keep the language. That bill failed, so we had to vote on it right away on the floor, and it passed. So, we have funded this before. That funding led to the receipt of quite significant federal and private foundation money. There might have been some other states involved as well. Doctor Berg has done a lot of research on this and is recognized as an expert around the country.

Rep. Weisz: The money that was used to develop the body of research that our committee received. He was able to come to us to request this. He was very confident that now they know enough that they can have an intervention that can affect that 30% minimum they he thinks they can address.

Rep. Ekstrom: Where is the FAS Center located?

Rep. Weisz: UND.

Rep. Ekstrom: Are other states are pursuing this type of thing?

Rep. Weisz: Dr. Byrd is world renowned. He has presented testimony in other states and around the world, but this would put us at the leading edge.

Rep. Hawken: I testified before your committee a few days ago on a bill that would have increased the level of prenatal healthcare for women who are uninsured or underinsured. It is my understanding that came out with a Do Not Pass. If we do that the first time, there won't be babies with FAS. This is a good bill, but there is more than one piece to get past this problem. Having prenatal care for women when they get pregnant the first time, could probably be a greater percentage than 30%.

Rep. Weisz: I don't disagree that prenatal care is important. This goes beyond that. The mothers know drinking is not right. This is about actual intervention efforts. It is outside of prenatal care in a sense.

Rep. Nelson: What does the appropriation do? Outreach from Grand Forks would be necessary to reach the people that are desired? Can you explain the intervention process?

Rep. Weisz: They identify the women that have had a FAS baby. They will go to these women, intervene, and do the things necessary to prevent this from happening again. The mother can refuse the service. They will go where ever they are in the state.

Rep. Nelson: Is there a community presence that is available, or does the intervention team come from UND?

Rep. Weisz: They can and do coordinate with others, but there is \$12,500 for travel. They will go out and work with the local services as well.

Rep. Wald: Have they identified any particular population group that has a higher incident rate, and would this qualify for any stimulus money?

Rep. Weisz: The Native American population has the highest incidence. I'm not aware of anything that I have seen that indicates that stimulus money could be used.

Rep. Williams moved a Do Pass on SB 2412.

Rep. Klein seconded the motion.

Rep. Pollert: How many cases are there potentially? \$164,000 is maybe two or three people for one year for personnel. How many cases can they handle? They can't hold their hands when they go out at night.

Rep. Weisz: It's not their responsibility to hold their hands. They are projecting 70 new cases next year. It's their job to identify the women who would benefit and get them into the program. They help the local providers. Their goal is to help at least 30 percent. Remember \$2.4 million dollars to provide for one of these children. It's a given, that you and I will pay the costs to care for these children for the remainder of their lives.

Rep. Delzer: Did you check into the availability of treatment centers and where will the funding come from for the treatment?

Rep. Weisz: The funding for the Medicaid comes from us. The assumption is that this intervention is cheaper than the consequences. Not just for the infant, but there is potential that the mother won't end up in the system as well.

Rep. Berg: I'm probably looking at this all wrong, but we're spending \$2.2 billion. This is expensive to treat. We all know you shouldn't drink when you're pregnant. We also know that there is huge savings. Why do we have to have legislative action to deal with something that apparently everyone within Human Services understands? Wouldn't it be more effective to have consequences for women who put their children at risk? Why do we have to start a new program?

Rep. Weisz: I'm strong supporter of personal responsibility. What do we do if they are not responsible? We can't force them not to drink. Are we going to lock them in jail? They are already on our system in TANF or welfare. We all agree that this shouldn't happen. It shouldn't even be an issue, **but it is**. We take care of them on the back end regardless. We can tell them that they won't get any services, but who is going to take care of that baby?

Page 5

House Appropriations Committee

Bill/Resolution No. SB ~~4212~~ 2412

Hearing Date: 03/19/09

A roll call vote was taken. **Aye 18 Nay 5 Absent 2**

The motion carried.

Representative Holman will carry SB 2412.

Date: 3/19/09
 Roll Call Vote #: 1

2009 HOUSE STANDING COMMITTEE ROLL CALL VOTES
 BILL/RESOLUTION NO. 2412

Full House Appropriations Committee

Conference Committee

Legislative Council amendment Number _____

Action Taken: Do Pass Do Not Pass As Amended

Motion Made By: Williams Seconded By: Klein

| Representatives | Yes | No | Representatives | Yes | No |
|-------------------------|-----|----|-----------------|-----|----|
| Chairman Svedjan | | ✓ | | | |
| Vice Chairman Kempenich | ✓ | | | | |
| Rep. Skarphol | ✓ | | Rep. Kroeber | ✓ | |
| Rep. Wald | ✓ | | Rep. Onstad | ✓ | |
| Rep. Hawken | ✓ | | Rep. Williams | ✓ | |
| Rep. Klein | ✓ | | | | |
| Rep. Martinson | ✓ | | | | |
| Rep. Delzer | | ✓ | Rep. Glassheim | ✓ | |
| Rep. Thoreson | ✓ | | Rep. Kaldor | ✓ | |
| Rep. Berg | | ✓ | Rep. Meyer | ✓ | |
| Rep. Dosch | ✓ | | | | |
| Rep. Pollert | | ✓ | Rep. Ekstrom | ✓ | |
| Rep. Bellew | ✓ | | Rep. Kerzman | ✓ | |
| Rep. Kreidt | | ✓ | Rep. Metcalf | ✓ | |
| Rep. Nelson | ✓ | | | | |
| Rep. Wieland | ✓ | | | | |

Total Yes 18 No 5

Absent 2

Floor Assignment: Rep. Helman

If the vote is on an amendment, briefly indicate intent:

REPORT OF STANDING COMMITTEE (410)
March 19, 2009 4:05 p.m.

Module No: HR-50-5424
Carrier: Holman
Insert LC: . Title: .

REPORT OF STANDING COMMITTEE

SB 2412, as engrossed: Appropriations Committee (Rep. Svedjan, Chairman)
recommends **DO PASS** (18 YEAS, 5 NAYS, 2 ABSENT AND NOT VOTING).
Engrossed SB 2412 was placed on the Fourteenth order on the calendar.

2009 TESTIMONY

SB 2412

MATERNAL RISK SCORE

SCORE

- Age over 25 years *check any one, add 5*
- Did not graduate from high school
- Unmarried, divorced, widow, living with partner
- Poor diet
- Smokes more than 1/2 pack per day
- On AFDC, WIC, Social Security or income < \$16,000 per year

- Drinks, but less than the criteria for heavy drinker *check here, add 20*

- Age first drunk less than 15 years
- In treatment over three times
- In treatment in last 12 months *check any one, add 35*
- Previous child with FASD, birth defect or developmental disability
- Previous child died
- Children out of home (foster care or adopted)

- Heavy drinker (drinks 3 or more drinks/day for 3 or more days per week, or more than 5 drinks/day on 6 or more occasions) *check any one, add 45*
- Uses inhalants, sniffs, huffs or illegal drugs

Score-Risk Category-Recommendations

| | | | |
|--------|-----------|--|-------------|
| 0 | None | Standard prenatal care | Total Score |
| 5 | Low | Standard prenatal care | |
| 20-40 | Moderate | Standard prenatal care and patient education on FASD | |
| 45-50 | High | High risk pregnancy, alcohol-drug abuse treatment | |
| 55-105 | Very High | High risk pregnancy, inpatient treatment | |

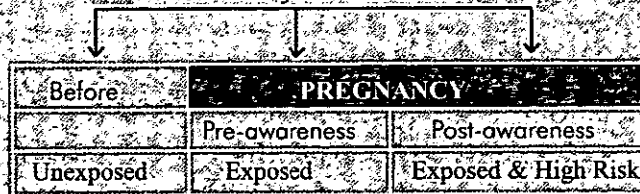
**Risk and Exposure Assessment:
Fetal Alcohol Spectrum Disorders**

Larry Burd, Ph.D., Director
North Dakota Fetal Alcohol Syndrome Center
laburd@medicine.nodak.edu

Additional information on FASD and Related Disorders at
www.online-clinic.com

FASD Cost and Prevalence Calculator
FAS Community Assessment Tool
Prenatal Alcohol Exposure Model

When was your last drink?



UND UNIVERSITY OF NORTH DAKOTA

**SCREENING FOR ALCOHOL ABUSE
ASSESSMENT OF EXPOSURE DURING PREGNANCY**

- On average how many days per week did you drink during pregnancy? _____ (a)
- On an average drinking day during pregnancy how many drinks did you have? _____ (b)
- How many days per month did you have 4 or more drinks during pregnancy? _____ (c)
- What is the most you had to drink on any one day during pregnancy? _____ (d)

EXPOSURE PARAMETERS

(Cumulative exposure during pregnancy)

Pregnancy Drinking Days = (a x 40) = _____ (e)
Estimates number of drinking days during pregnancy.

Percent of Days Exposed During Pregnancy
Estimates days exposed during pregnancy. = (e ÷ 280) = _____

Number of Binge Days (4 or more drinks in one day) = (c x 9) = _____
Estimates number of binge days.

Number of Drinks During Pregnancy = (a x b x 40) = _____ (f)
Estimates cumulative number of drinks during pregnancy.

Ounces of absolute alcohol = (f ÷ 2) = _____
Estimates cumulative absolute alcohol exposure during pregnancy.

Number of Drinks During Pregnancy

On average, how many days per week did you drink?

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|-----------|-----|-------|-------|-------|-------|-------|-------|
| 1 | 40 | 80 | 120 | 160 | 200 | 240 | 280 |
| 2 | 80 | 160 | 240 | 320 | 400 | 480 | 560 |
| 3 | 120 | 240 | 360 | 480 | 600 | 720 | 840 |
| 4 | 160 | 320 | 480 | 640 | 800 | 960 | 1,120 |
| 5 | 200 | 400 | 600 | 800 | 1,000 | 1,200 | 1,400 |
| 6 | 240 | 480 | 720 | 960 | 1,200 | 1,440 | 1,680 |
| 7 | 280 | 560 | 840 | 1,120 | 1,400 | 1,680 | 1,960 |
| 8 | 320 | 640 | 960 | 1,280 | 1,600 | 1,920 | 2,240 |
| 9 | 360 | 720 | 1,080 | 1,440 | 1,800 | 2,160 | 2,520 |
| 10 | 400 | 800 | 1,200 | 1,600 | 2,000 | 2,400 | 2,800 |
| 11 | 440 | 880 | 1,320 | 1,760 | 2,200 | 2,640 | 3,080 |
| 12 | 480 | 960 | 1,440 | 1,920 | 2,400 | 2,880 | 3,360 |
| 13 | 520 | 1,040 | 1,560 | 2,080 | 2,600 | 3,120 | 3,640 |
| 14 | 560 | 1,120 | 1,680 | 2,240 | 2,800 | 3,360 | 3,920 |
| 15 | 600 | 1,200 | 1,800 | 2,400 | 3,000 | 3,600 | 4,200 |

On an average drinking day, how many drinks did you have?

Chairman Lee and Committee Members:

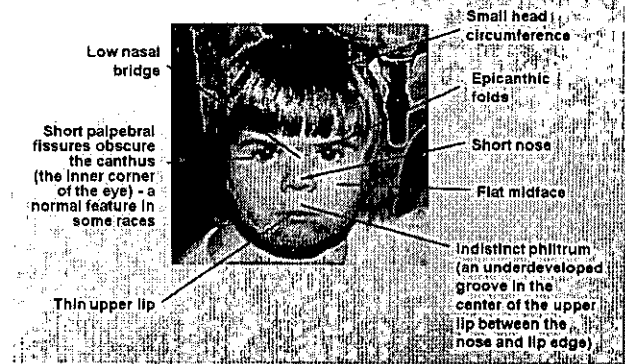
My name is Larry Burd. I am a Professor of Pediatrics at the University of North Dakota School of Medicine and Health Sciences. I have been at the University for 29 years. During this time I have evaluated over 14,000 children from every county in our state. It would be difficult to find a city in North Dakota where I have not seen a family for help.

In my clinical service I see children of all ages with autism, mental retardation, birth defects and other developmental disorders. Today I am not here for them, but rather to ask for help for children and families who are affected by fetal alcohol spectrum disorders (FASD).

The figure demonstrates the diagnostic criteria for FASD.

- Alcohol exposure during pregnancy
- Brain damage
- Growth impairments
- Common associated conditions:
 - Birth defects of the heart
 - Visual impairment
 - Mental illness
 - Substance abuse
 - Behavior Disorders

Fetal Alcohol Spectrum Disorder

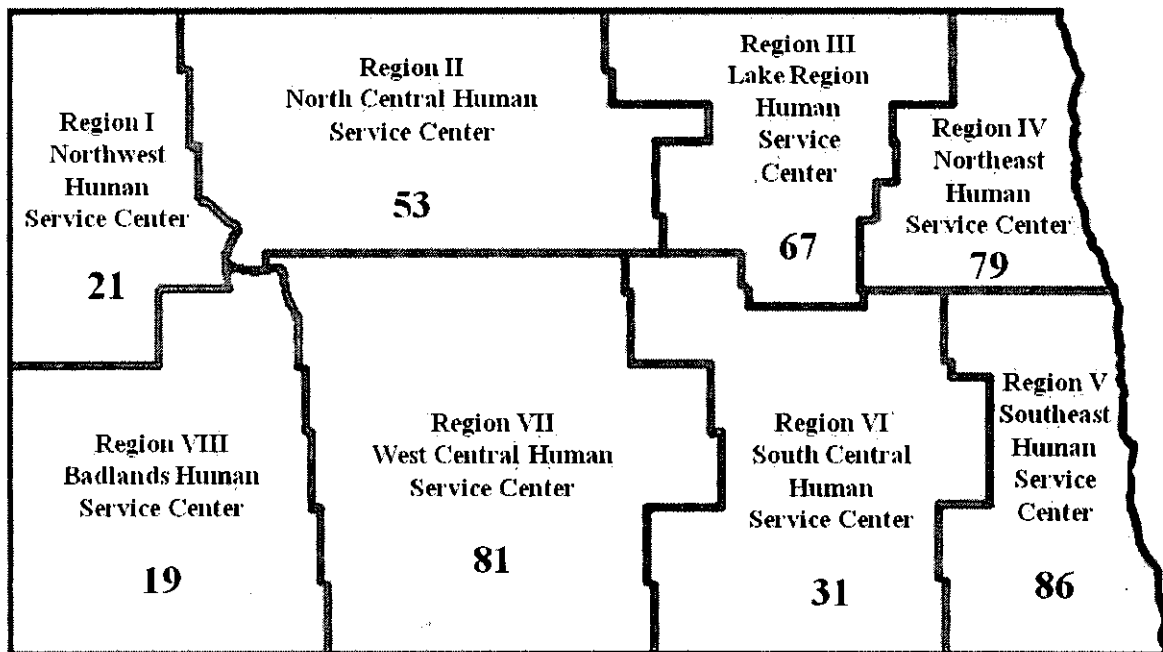


North Dakota currently has over 400 diagnosed cases of FASD. We have many more who are undiagnosed.

FASD is preventable, highly recurrent, and severe. One unusual feature of FASD is the recurrence rate which exceeds 70% and is likely the most recurrent in

medicine. As a result, most children with FASD have affected siblings. I consider this to be a public health tragedy.

We have families with FASD from every area in our state. The figure indicates the distribution of cases in each region of North Dakota. No area of the state is unaffected by FASD.



FASD is a disorder of lifelong disability, increased mortality, and is an unusually costly disorder. The lifetime cost of care exceeds \$2.4 million for each affected person. The data here is not adapted from other states but represents costs for North Dakota. In addition to the large commitments from the families (many of whom have adopted these children) the care for most of these affected people are or will be covered by Medical Assistance.

As a part of my research to improve diagnosis and prevention of FASD, I have participated in over \$14 million in federally funded research. We have had projects on

every reservation and two of these programs have been ongoing in these communities for over 20 consecutive years. However, in much of the state when the FASD funding ends the prevention efforts stop. While we know how to prevent many cases of FASD, we simply do not have the funding to do it.

In my opinion prevention is the only way to reduce new cases. We have demonstrated three effective strategies to prevent FASD.

The first is to identify alcohol abuse early. In our studies we have shown that most cases of alcohol abuse in pregnant women go undetected. Early identification of drinking during pregnancy is the first key. Currently, less than 5% of pregnant women who have problem drinking during pregnancy are detected. We use the clinical guides and pens I have given you to demonstrate to physicians and prenatal care providers how to ask about and record the important data in the patients chart. Recognition of alcohol use is the key to prevention.

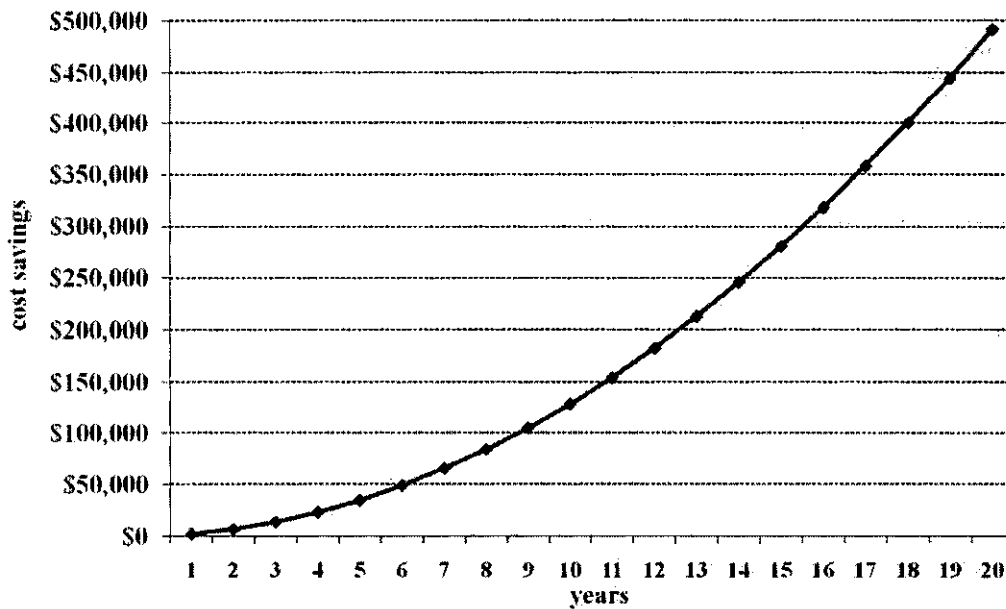
The second key is to recognize that much alcohol abuse during pregnancy is obscured by other drug use and smoking. Our current methamphetamine epidemic has received wide public attention. However, most of these women also abuse alcohol and smoke. Alcohol use is far more harmful to the developing fetus than exposure to meth. Prevention of alcohol exposure will eliminate much of the risk in these pregnancies.

The third key is prevention of recurrence. FASD is not a problem where many women each have an affected child but rather where a few

women have several affected children. We have demonstrated how to prevent recurrence. We now need to implement these strategies.

I am not here to suggest that we can prevent all future cases of FASD. But we have demonstrated we can now prevent one third of new cases.

I have included for your review actual health care cost data from our state to demonstrate the benefits of prevention of only one case of FASD each year.



These cost savings from prevention do not include other costs for early intervention, special education, juvenile justice, residential care, or for care as adults from developmental disabilities. I know of no other disorder where the benefits of prevention exceed those for FASD.

I have been treating FASD for over 35 years. Very few people with FASD will ever live independently. Without your help we will continue to spend huge sums on treatment. In this difficult economic climate it seems like a bargain to spend one to two percent of the cost of care to prevent a new case of FASD.

I hope you will carefully consider helping us find the resources to prevent new cases of FASD in our state. North Dakota is nationally recognized for our FASD research and prevention efforts and I have been to over forty states to help in development of FASD prevention and treatment strategies. In these states I always conclude with the same message.

If we meet again next year, North Dakota
will have 70 new cases of FASD.
What have you done to prevent them?

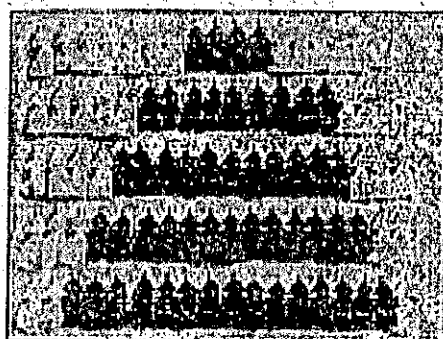
I would like to conclude with a few posters from over 100 years ago about this problem and one of our FASD prevention posters.

Thank you for your valuable time.

Drinking Mothers Lost More than Half their Babies Sober Mothers Less than One-fourth

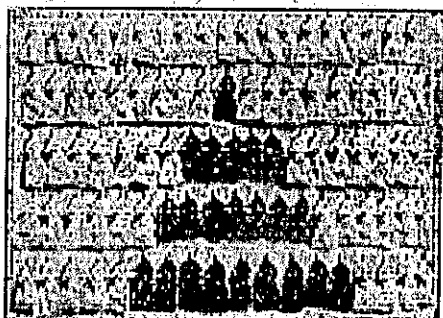
Mortality of Children of 21 DRINKING Mothers

Children 6 Years Old Under Ten Years — 45 PER CENT



Mortality of Children of 28 SOBER Mothers

Children 6 Years Old Under Ten Years — 23 PER CENT



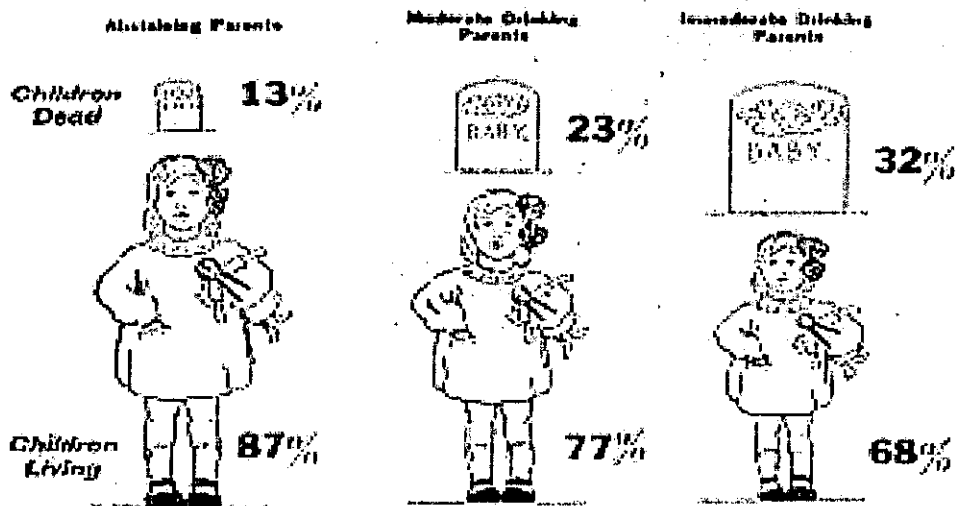
The Sober Mothers were relatives of the Drinking Mothers and had Sober Husbands

W. C. Sullivan, M. D., "Alcoholism," 1916.

EDUCATED BY
BY SCIENTIFIC RESEARCH FEDERATION
MADISON, WIS.

PRINTED BY
AMERICAN TRUST PRINTING COMPANY
ADELPHI, OHIO.

Child Death Rate Higher IN Drinkers' Families



Abstaining parents had never drunk alcoholic liquors, or at least since marriage.
 "Moderates" drink no more daily than corresponded to one glass of 4% beer.
 "Immoderates" drink daily more than the above-named amount.

Excessive Death-Rate in Drinking Homes Cost 2,407 Children Their Lives

Statistics of 19,519 children in 5,736 families. Laidlaw N.L. International Congress on Alcoholism, 1929. Abstaining families lost 13 per cent of children by death. At the same rate drinking parents would have lost 7,156 children. They actually lost 4,563, an excess of 2,607.

COPYRIGHT, 1931
 BY SCIENTIFIC TEMPERANCE FEDERATION
 CHICAGO, ILL.

PUBLISHED BY
 AMERICAN CIGARETTE MANUFACTURING COMPANY
 NEW YORK, N. Y.

WHY AMERICA WENT DRY

Beer Doubled The Child Death-Rate

IN THE FIRST FIVE YEARS OF LIFE

All in the same village. Beer practically the only drink used by the parents and not always immoderately.



Children of Sober Parents

23% DIED

(18.6% in first year)



Children of
Beer Drinkers

45% DIED

(36% in first year)

**Alcohol whether in Beer or in Whisky
is an Enemy to Child Life.**

120 Sober Families with 650 Children.
18 Beer-Drinking Families with 125 Children.
All strictly comparable and free from hereditary diseases.

Joseph Kitch: Alcohol and Child Mortality in Lurganboro, Austria.
Scientific Temperance Journal, Dec., 1913

MANUFACTURED BY
BY BROTHERHOOD OF CHRISTIAN SCIENCE
DEPT. OF TRADE,
PRINTED IN U. S. A.

THE NEW GRAN BROS. PUBLISHER CO.
WESTERVILLE, OHIO



Parents' Drinking Weakens Children's Vitality

Comparison of Children in 50 Abstaining and 50 Drinking Families
in One Village in Finland

WEAKLY CHILDREN

In Abstaining Families

 13%

In Drinking Families

 82%

CHILDREN WHO DIED

In Abstaining Families

 18.5%

In Drinking Families

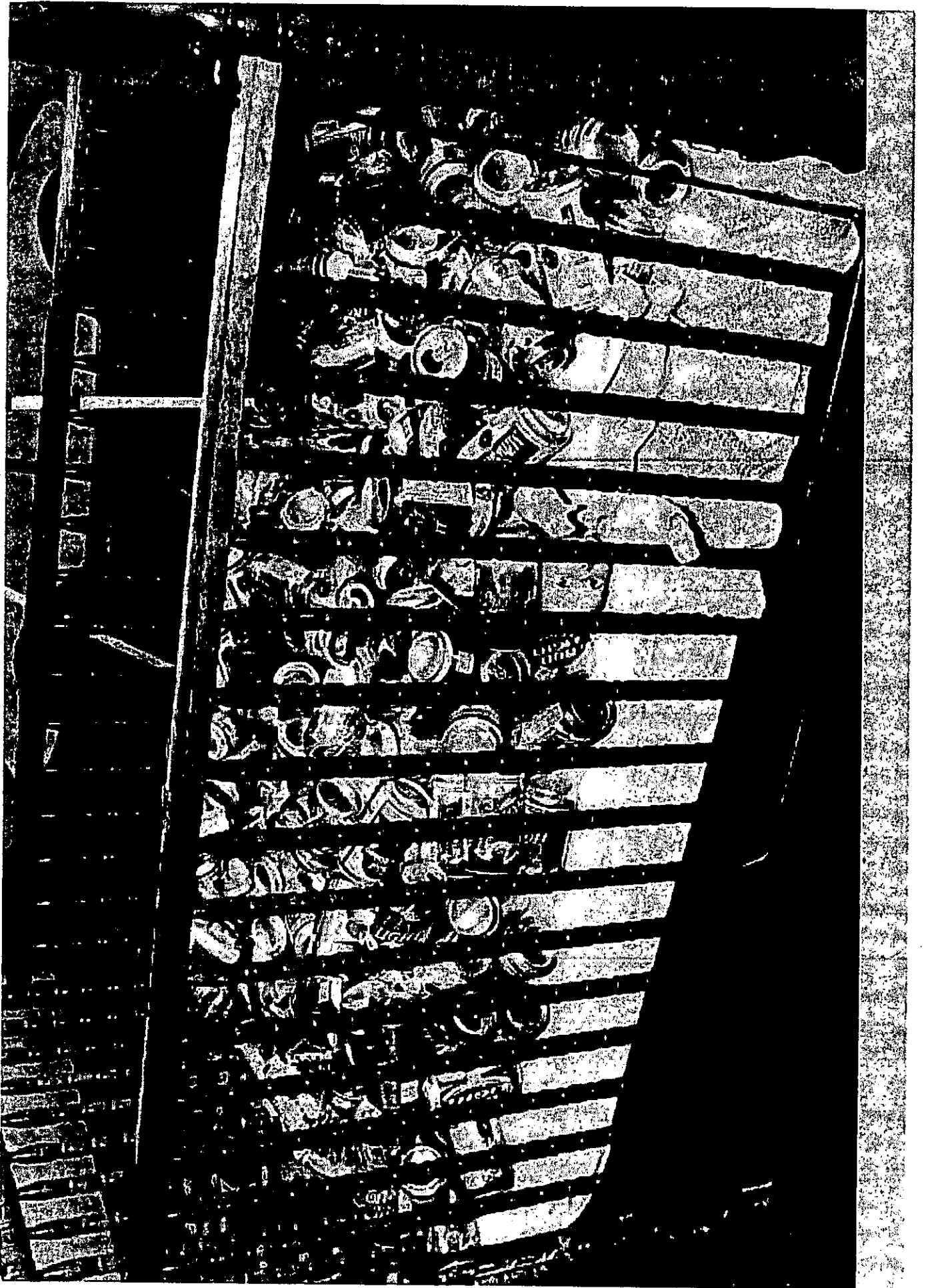
 24.8%

DRINK MENACES VIGOR AND LIVES OF CHILDREN

Prof. Taav. Laitinen, University of Helsinki, Report XII International
Congress vs. Alcoholism, 1959.

COPYRIGHT 1961
BY SCIENTIFIC TEMPERANCE FEDERATION
LONDON, ENGLAND

PUBLISHED BY
AMERICAN TEMPERANCE PUBLISHING COMPANY
BOSTON, MASS.



Good Morning

I am here to testify on behalf of sb 2412 to appropriate funds for the North Dakota Fetal Alcohol Syndrome center. These funds will be used for prevention, early identification and improved treatment for FAS kids in ND. We understand that the cost of care for a child with FAS will exceed 2 million dollars over the course of their lifetime. We have one of these million dollar kids with FAS. Sterling came to live us 5 years ago and we adopted him. Because Sterlings mother drank during her pregnancy, Sterling, now at age 12, weighs 38 pounds, and has had 27 surgeries during his life including heart valve replacement and a pace maker. To put this in perspective, my 4 year old grandson out weighs sterling by 10 pounds. This is one of the many features that Fas presents. The main damage is the brain damage that occurs from the prenatal alcohol exposure. We are now entering a phase where his heart condition is some stable but his learning disabilities and behaviors at school are on more concern. We have worked with infant development, preschool special education, special education, Psychiatrists, medications for behavior, physiologists, and the ND FAS center, only to find these learning problems and behaviors will worsen over time. The ND FAS center, and Dr.Byrd, have been the greatest resource and source of hope for us. I'm not sure we could give sterling the care he needs without them.

In taking care of sterling, we often wonder where was the prevention that would allow him to have a normal life. FAS is preventable- when women don't drink during their pregnancy, they have a zero risk for FAS. Steling has a brother with FAS and most children with FAS have affected siblings. While the interventions and help we receive will greatly improve the out come for sterling, none will give him an undamaged heart and normal brain, and the chance at a normal life the rest of us have. Only prevention can do this. All his life, Sterling will

need help. We need improved services for him, but most importantly we need prevention. *for others*

Chairman Holmberg and Committee Members:

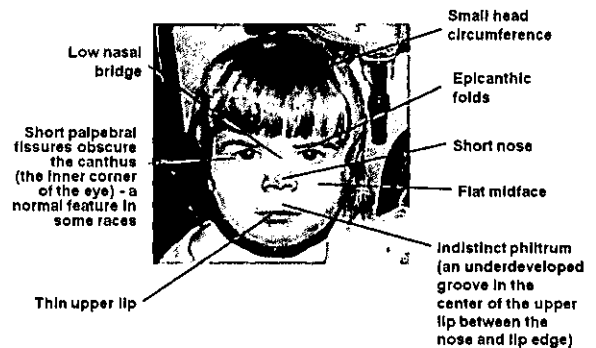
My name is Larry Burd. I am a Professor of Pediatrics at the University of North Dakota School of Medicine and Health Sciences. I have been at the University for 29 years. During this time I have evaluated over 14,000 children from every county in our state. It would be difficult to find a city in North Dakota where I have not seen a family for help.

In my clinical service I see children of all ages with autism, mental retardation, birth defects and other developmental disorders. Today I am not here for them, but rather to ask for help for children and families who are affected by fetal alcohol spectrum disorders (FASD).

The figure demonstrates the diagnostic criteria for FASD.

- Alcohol exposure during pregnancy
- Brain damage
- Growth impairments
- Common associated conditions:
 - Birth defects of the heart
 - Visual impairment
 - Mental illness
 - Substance abuse
 - Behavior Disorders

Fetal Alcohol Spectrum Disorder



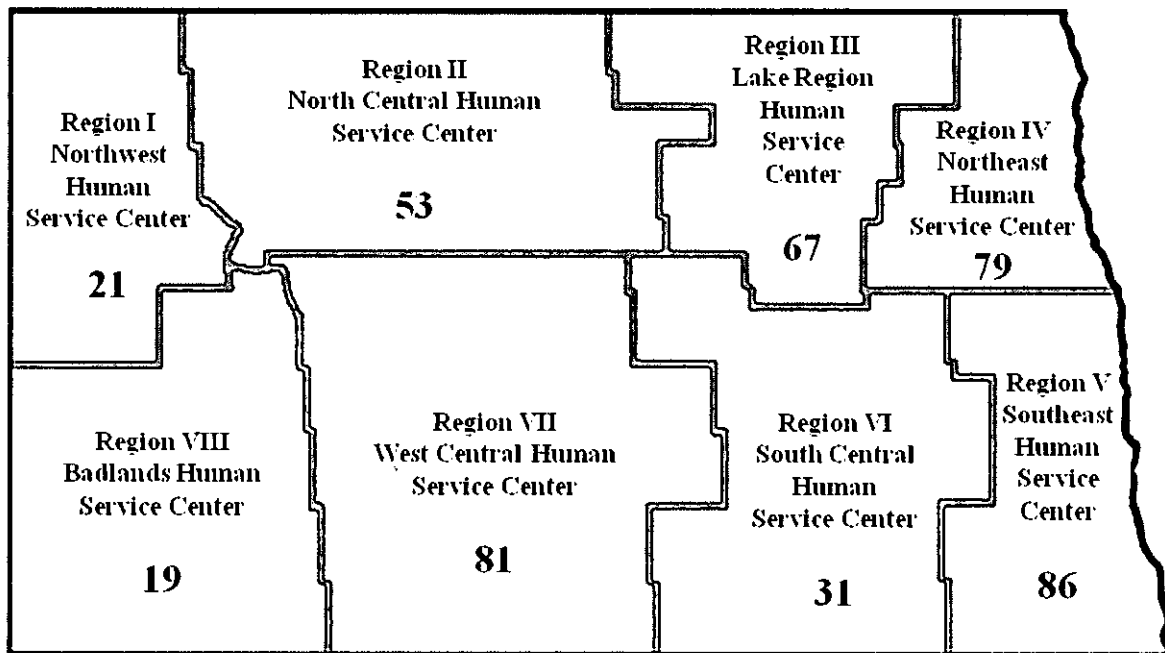
North Dakota currently has over 400 diagnosed cases of FASD. We have many more who are undiagnosed.

FASD is preventable, highly recurrent, and severe. One unusual feature of FASD is the recurrence rate which exceeds 70%. This may be the most recurrent

disorder in medicine. As a result, most children with FASD have affected siblings. I consider this to be a public health tragedy.

We have families with FASD from every area in our state. The figure indicates the distribution of cases in each region of North Dakota. No area of the state is unaffected by FASD.

FASD Cases By Region



FASD is a disorder of lifelong disability, increased mortality, and is an unusually costly disorder. The lifetime cost of care exceeds \$2.4 million for each affected person. The data here is not adapted from other states but represents costs for North Dakota. In addition to the large commitments from the families (many of whom have adopted these children) the care for most of these affected people is or will be covered by Medical Assistance.

As a part of my research to improve diagnosis and prevention of FASD, I have participated in over \$14 million in federally funded research. We have had projects on every reservation and two of these programs have been ongoing in these communities for over 20 consecutive years. However, in much of the state when the FASD funding ends the prevention efforts stop. While we know how to prevent many cases of FASD, we simply do not have the funding to do it.

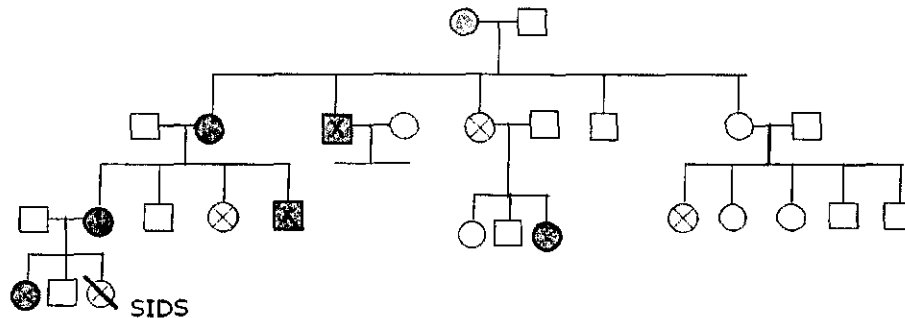
We have demonstrated three effective strategies to prevent FASD.

The first key is to identify alcohol abuse early. In our studies we have shown that most cases of alcohol abuse in pregnant women go undetected. Currently, less than 5% of pregnant women drinking during pregnancy are detected. The clinical guides and pens I have given you demonstrate how to ask about and record the important data in the patients chart. Recognition of alcohol use is the key to prevention.

The second key is to recognize that much alcohol abuse during pregnancy is obscured by other drug use. Our current methamphetamine epidemic has received wide public attention. However, most of these women also abuse alcohol and smoke. Alcohol use is far more harmful to the developing fetus than exposure to meth. Prevention of alcohol exposure will eliminate much of the risk in these pregnancies.

The third key is prevention of recurrence. FASD is not a problem where many women each have an affected child but rather where a few women have several affected children. We have demonstrated how to prevent recurrence. We now need to implement these strategies.

FASD – Familial and Generational

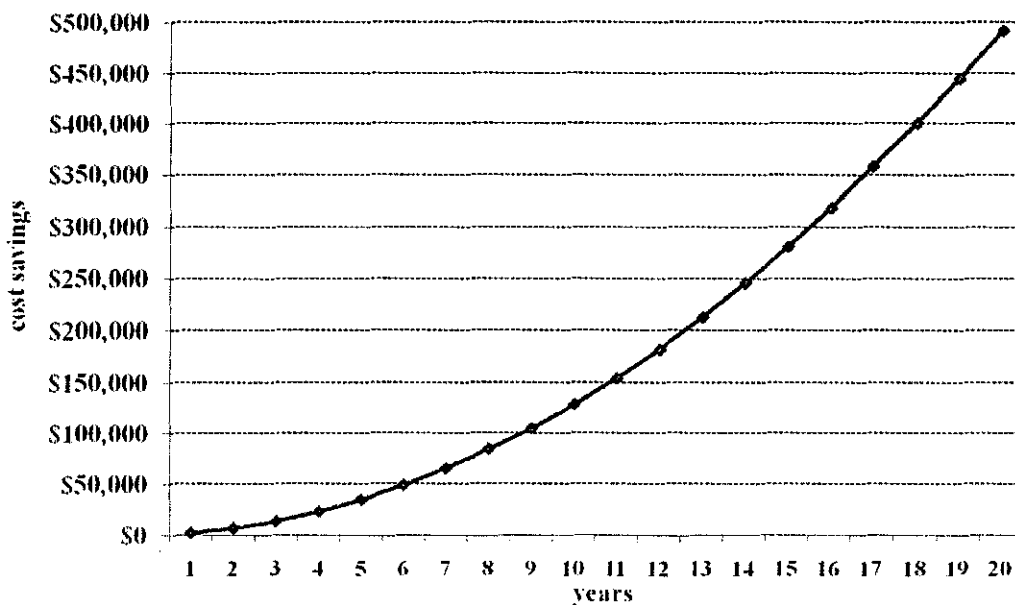


- FAS - Red
- Yellow
- ARND - Green

I am not here to suggest that we can prevent all future cases of FASD. But we have demonstrated we can now prevent one third of new cases.

I have included for your review actual health care cost data from our state to demonstrate the benefits of prevention of only one case of FASD each year.

Additional Health Costs for FASD \$2,342 per year



This does not include even larger savings from reduction in special education, juvenile justice, residential care, or for care as adults from developmental disabilities. I know of no other disorder where the benefits of prevention exceed those for FASD.

I have been treating FASD for over 35 years. Very few people with FASD will ever live independently. In this difficult economic climate it seems like a bargain to spend one to two percent of the cost of care to prevent a new case of FASD.

Budget

North Dakota Fetal Alcohol Syndrome Center

FAS Center Staff

Prevention - Prevention Data Management Services Coordinator

Intervention Services Coordinator - Coordinator of FAS Services
in North Dakota

Screening and Early Identification Coordinator to develop
screening for FAS in North Dakota

Fringe Benefits

| | |
|---|------------------|
| Personnel | \$164,950 |
| Travel per diem | 12,500.00 |
| Printing, Postage, Telephone | 4,900.00 |
| Supplies, Prevention Materials, Computer and Software | <u>2,800.00</u> |
| Annual Costs | \$184,950 |
| Total Biennial Cost | \$369,900 |

I hope you will carefully consider helping us find the resources to prevent new cases of FASD in our state. North Dakota is nationally recognized for our FASD research and prevention efforts and I have been to over forty states to help in development of FASD prevention and treatment strategies. In these states I always conclude with the same message.

If we meet again next year, North Dakota
will have 70 new cases of FASD.
What have you done to prevent them?

I would like to conclude with a few posters from over 100 years ago about this problem and one of our FASD prevention posters.

Thank you for your valuable time.

Chairman Weisz and Committee Members:

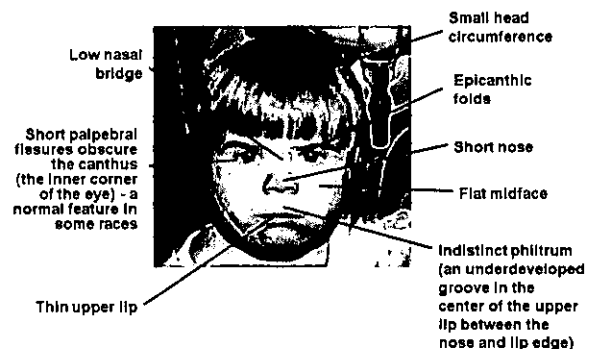
My name is Larry Burd. I am a Professor of Pediatrics at the University of North Dakota School of Medicine and Health Sciences. I have been at the University for 29 years. During this time I have evaluated over 14,000 children from every county in our state. It would be difficult to find a city in North Dakota where I have not seen a family for help.

In my clinical service I see children of all ages with autism, mental retardation, birth defects and other developmental disorders. Today I am not here for them, but rather to ask for help for children and families who are affected by fetal alcohol spectrum disorders (FASD).

The figure demonstrates the diagnostic criteria for FASD.

- Alcohol exposure during pregnancy
- Brain damage
- Growth impairments
- Common associated conditions:
 - Birth defects of the heart
 - Visual impairment
 - Mental illness
 - Substance abuse
 - Behavior Disorders

Fetal Alcohol Spectrum Disorder



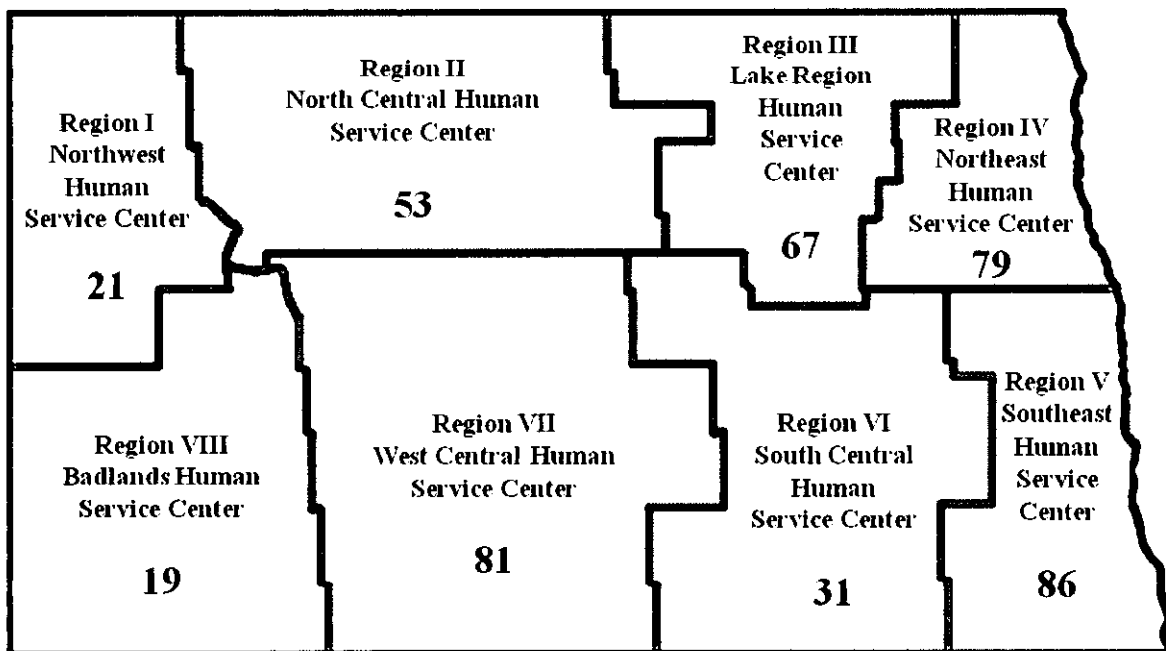
North Dakota currently has over 400 diagnosed cases of FASD. We have many more who are undiagnosed.

FASD is preventable, highly recurrent, and severe. One unusual feature of FASD is the recurrence rate which exceeds 70%. This may be the most recurrent

disorder in medicine. As a result, most children with FASD have affected siblings. I consider this to be a public health tragedy.

We have families with FASD from every area in our state. The figure indicates the distribution of cases in each region of North Dakota. No area of the state is unaffected by FASD.

FASD Cases By Region



FASD is a disorder of lifelong disability, increased mortality, and is an unusually costly disorder. The lifetime cost of care exceeds \$2.4 million for each affected person. The data here is not adapted from other states but represents costs for North Dakota. In addition to the large commitments from the families (many of whom have adopted these children) the care for most of these affected people is or will be covered by Medical Assistance.

As a part of my research to improve diagnosis and prevention of FASD, I have participated in over \$14 million in federally funded research. We have had projects on every reservation and two of these programs have been ongoing in these communities for over 20 consecutive years. However, in much of the state when the FASD funding ends the prevention efforts stop. While we know how to prevent many cases of FASD, we simply do not have the funding to do it.

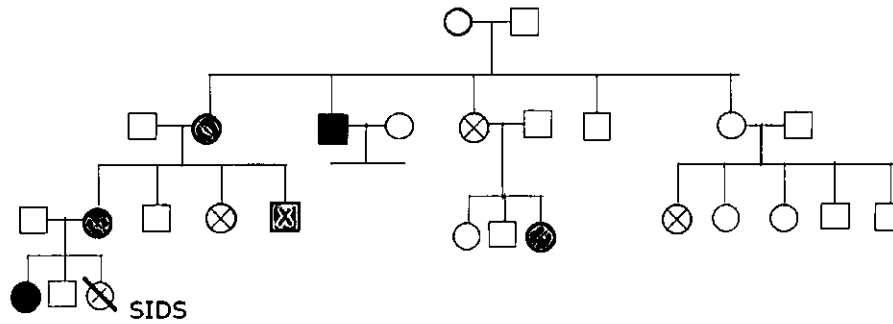
We have demonstrated three effective strategies to prevent FASD.

The first key is to identify alcohol abuse early. In our studies we have shown that most cases of alcohol abuse in pregnant women go undetected. Currently, less than 5% of pregnant women drinking during pregnancy are detected. The clinical guides and pens I have given you demonstrate how to ask about and record the important data in the patients chart. Recognition of alcohol use is the key to prevention.

The second key is to recognize that much alcohol abuse during pregnancy is obscured by other drug use. Our current methamphetamine epidemic has received wide public attention. However, most of these women also abuse alcohol and smoke. Alcohol use is far more harmful to the developing fetus than exposure to meth. Prevention of alcohol exposure will eliminate much of the risk in these pregnancies.

The third key is prevention of recurrence. FASD is not a problem where many women each have an affected child but rather where a few women have several affected children. We have demonstrated how to prevent recurrence. We now need to implement these strategies.

FASD – Familial and Generational

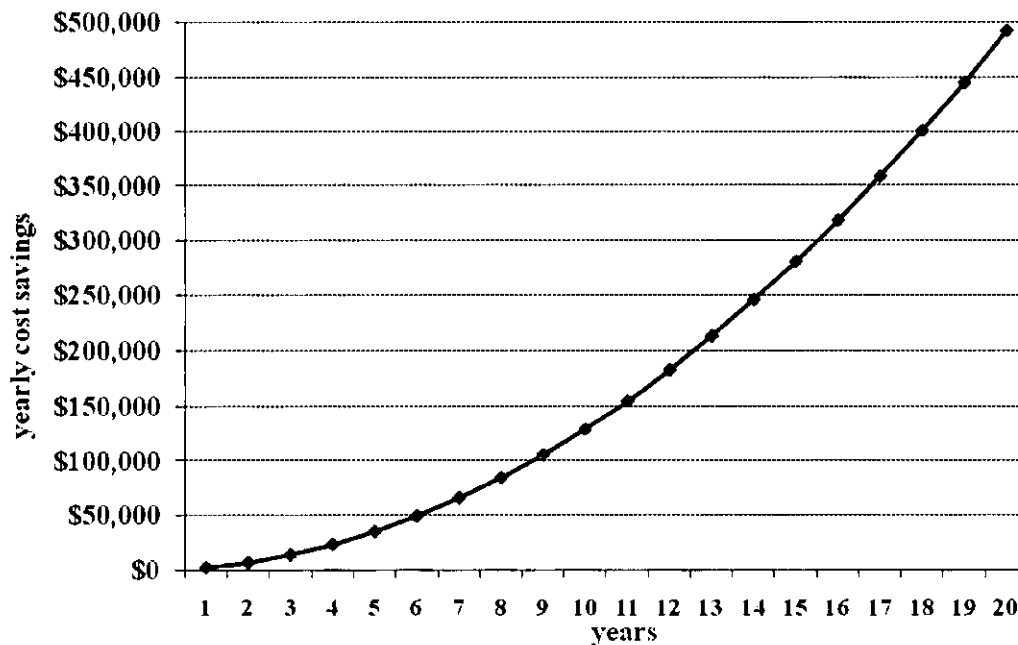


- FAS** - Red
- PFAS** - Yellow
- ARND** - Green

I am not here to suggest that we can prevent all future cases of FASD. But we have demonstrated we can now prevent one third of new cases.

I have included for your review actual health care cost data from our state to demonstrate the benefits of prevention of only one case of FASD each year.

Additional Health Costs for FASD \$2,342 per year



This does not include even larger savings from reduction in special education, juvenile justice, residential care, or for care as adults from developmental disabilities. I know of no other disorder where the benefits of prevention exceed those for FASD.

I have been treating FASD for over 35 years. Very few people with FASD will ever live independently. In this difficult economic climate it seems like a bargain to spend one to two percent of the cost of care to prevent a new case of FASD.

Budget

North Dakota Fetal Alcohol Syndrome Center

FAS Center Staff

| | |
|---|------------------|
| Personnel (Prevention and Intervention) | \$164,950.00 |
| Travel per diem | 12,500.00 |
| Printing, Postage, Telephone | 4,900.00 |
| Supplies, Prevention Materials, Computer and Software | <u>2,800.00</u> |
| Annual Costs | \$184,950 |
| Total Biennial Cost | \$369,900 |

I hope you will carefully consider helping us find the resources to prevent new cases of FASD in our state. North Dakota is nationally recognized for our FASD research and prevention efforts and I have been to over forty states to help in development of FASD prevention and treatment strategies. In these states I always conclude with the same message.

If we meet again next year, North Dakota
will have 70 new cases of FASD.
What have you done to prevent them?

I would like to conclude with a few posters from over 100 years ago about this problem and one of our FASD prevention posters.

Thank you for your valuable time.