2021 HOUSE HUMAN SERVICES

HCR 3011

2021 HOUSE STANDING COMMITTEE MINUTES

Human Services Committee
Pioneer Room, State Capitol

HCR 3011
1/18/2021

A concurrent resolution directing the legislative management to consider studying fetal alcohol spectrum disorders, including treatment, services available, potential prevention, and whether existing policies are appropriate

Chairman Weisz called the hearing to order at 10:28 am

Representatives	Roll Call
Representative Robin Weisz	P
Representative Karen M. Rohr	P
Representative Mike Beltz	P
Representative Chuck Damschen	P
Representative Bill Devlin	P
Representative Gretchen Dobervich	P
Representative Clayton Fegley	P
Representative Dwight Kiefert	P
Representative Todd Porter	P
Representative Matthew Ruby	P
Representative Mary Schneider	P
Representative Kathy Skroch	P
Representative Bill Tveit	P
Representative Greg Westlind	P

Discussion Topics:

- Substance Abuse Newborn Task Force
- Fetal Alcohol Syndrome Center
- ADHD – Fetal Alcohol

Rep. Bernie Satrom, District 12 (10:28), introduced the resolution, testified in favor, and submitted testimony #1191.

Jerry Bloemendaal, Parent Advocate, Jamestown, ND (10:38) testified in favor and submitted testimony #1032 and #1033.

Chairman Weisz closed the hearing at 10:45 am

Tamara Krause, Committee Clerk

HCR 3011

Good morning Chairman Weisz and members of the committee! For the record I am Rep. Bernie Satrom and am honored to serve the great people of District 12 in Jamestown.

In 2015 our legislature passed SB2367 which established the ND Task Force for Substance abused newborns. They identified a considerable lack of data on the incidence as well as effectiveness of measures to prevent and address it. As well as a lack of information on whether these problems are increasing or decreasing.

In 2019 Dr. Larry Burd from UND Published a Report to the ND Task Force on Substance Exposed Newborns which answered some of the questions.

This morning I bring before you a request for a followup study on the topic of Fetal Alcohol Syndrome.

Fetal Alcohol Syndrome or FAS is caused when a woman drinks alcohol while pregnant.

Drinking while pregnant can result in the child struggling with ADHD, Depression, Cognitive impairment, Intellectual Disability, Learning Disabilities, Substance abuse, Judgement Defects to name a few plus according to a Canadian study makes someone 19 times more likely to be incarcerated.

It is totally preventable.

ND Rates #3 in FASD births behind Wisconsin and the District of Columbia. Resulting in an estimated 330 FASD births at a cost of $1 million each over the first 43 years of life.

US as many as 16% of pregnant women with no history of alcohol dependence drank alcohol in the last month of pregnancy.

ND had 3400 women using alcohol during pregnancy in 2017 and there were 162 women who drank during all 40 weeks of pregnancy. Women who breastfeed caused increased rates of neurobehavioral and growth deficits.

Plus the negative of effects of drinking while pregnant are multigenerational. When A pregnant woman drinks she exposes herself the fetus and the fetal germline. Mothers of children with FASD have a 44.82 fold increase in mortality risk and 87% of the deaths occurred in women under the age of 50.

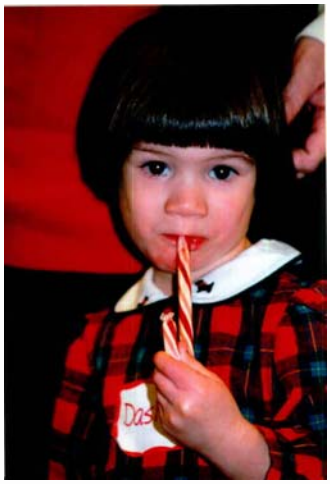
How can we reduce the prevalence of FASD? What should we do next? I think it is worth a followup conversation Lets do a study and figure it out.

Thank you for your time. I will stand for any questions.

Fetal Alcohol Spectrum Disorders

Fetal alcohol spectrum disorders (FASDs) can cause serious disabilities that last a lifetime. They can affect how a person looks, grows, learns, and acts. But, FASDs are 100% preventable—if a woman does not drink alcohol while she is pregnant.

- FASD is a term that describes the range of effects that can occur in a person whose mother drank alcohol while pregnant. These effects can include physical and mental disabilities and problems with behavior or learning. Often, a person has a mix of these problems. The term FASD is not intended for use as a clinical diagnosis.



- People with an FASD often have problems with learning, memory, attention span, problem solving, speech, and hearing. They are at very high risk for trouble in school, trouble with the law, alcohol and drug abuse, and mental health disorders.

- FASDs include fetal alcohol syndrome (FAS), which causes growth problems, abnormal facial features, and central nervous system problems. Children who do not have all of the symptoms of FAS can have another FASD. These children can have problems that are just as severe as those of children with FAS.

- It is not known exactly how many people have an FASD. Studies by the Centers for Disease Control and Prevention (CDC) have shown that 0.2 to 1.5 cases of FAS occur for every 1,000 live births in the United States. Other studies using different methods have estimated the rate of FAS at 0.5 to 2.0 cases per 1,000 live births. Scientists believe that there are at least four times as many cases of FASDs as FAS.

There is no known amount of alcohol use that is safe during pregnancy. There is no known time during pregnancy when alcohol use is safe.

- All drinks with alcohol can hurt an unborn baby. A 12-ounce can of beer has as much alcohol as a 4-ounce glass of wine or a 1-ounce shot of liquor. Some drinks, like malt beverages, wine coolers, and mixed drinks, have more alcohol than a 12-ounce can of beer.

- A woman should not drink any alcohol if she is pregnant or planning to get pregnant. If a woman could become pregnant, she should talk to her doctor and take steps to lower the chance of exposing her baby to alcohol.

- FASDs last a lifetime—there is no cure. But if children with an FASD are identified early, they can receive services to help increase their well-being.

- FASDs are 100% preventable—if a woman does not drink alcohol while she is pregnant.

#1033

A Report to North Dakota on Fetal Alcohol Exposure and Fetal Alcohol Spectrum Disorders

From North Dakota Fetal Alcohol Syndrome Center (2019)

Larry Burd, PhD
Director, North Dakota FAS Center
701-777-3683 larry.burd@UND.edu

Why emphasize prenatal alcohol exposure?

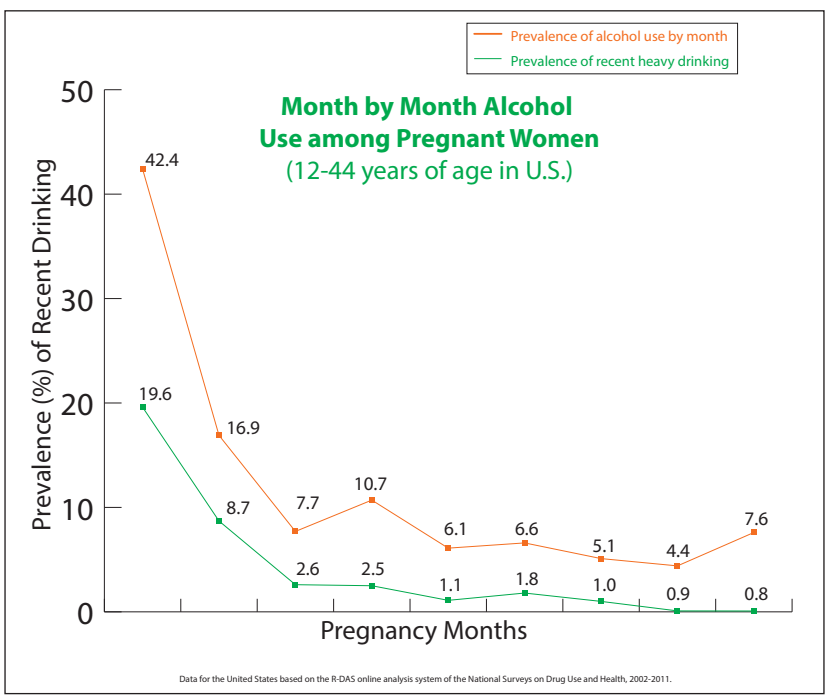
Prenatal alcohol exposure often occurs with other substance abuse and is often not detected. Of all the substances of abuse (including cocaine, heroin, and marijuana), alcohol produces by far the most serious adverse effects for the fetus.

Effect	Alcohol	Marijuana	Cocaine	Heroin	Tobacco
Low Birth Weight	■		■	■	■
Impaired Growth	■				
Facial Malformation	■				
Small Head Size	■				
Intellectual and Development Delays	■	■			
Hyperactivity, Inattention	■	■		■	■
Sleeping Problems	■	■	■	■	■
Poor Feeding	■		■		
Excessive Crying	■	■	■	■	
Higher Risk for Sudden Infant Death Syndrome	■			■	■
Organ Damage, Birth Defects	■				
Respiratory Problems	■			■	■

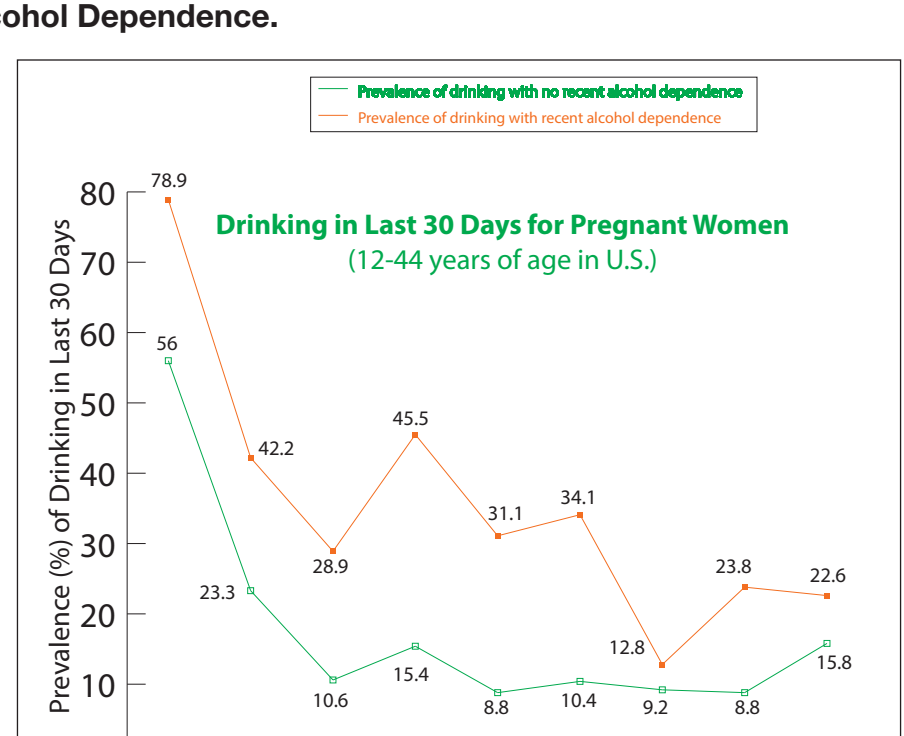
http://www.faslink.org/DrugEffectOnPrenatalDevelopment.html

Prevalence of Prenatal Alcohol Exposure

Two recent studies demonstrate the magnitude of prenatal alcohol exposure in the United States. This data is similar to rates obtained from four sites in North Dakota over the past 30 years.



Prenatal Alcohol Exposure is Increased in Women With Current or a History of Alcohol Dependence.



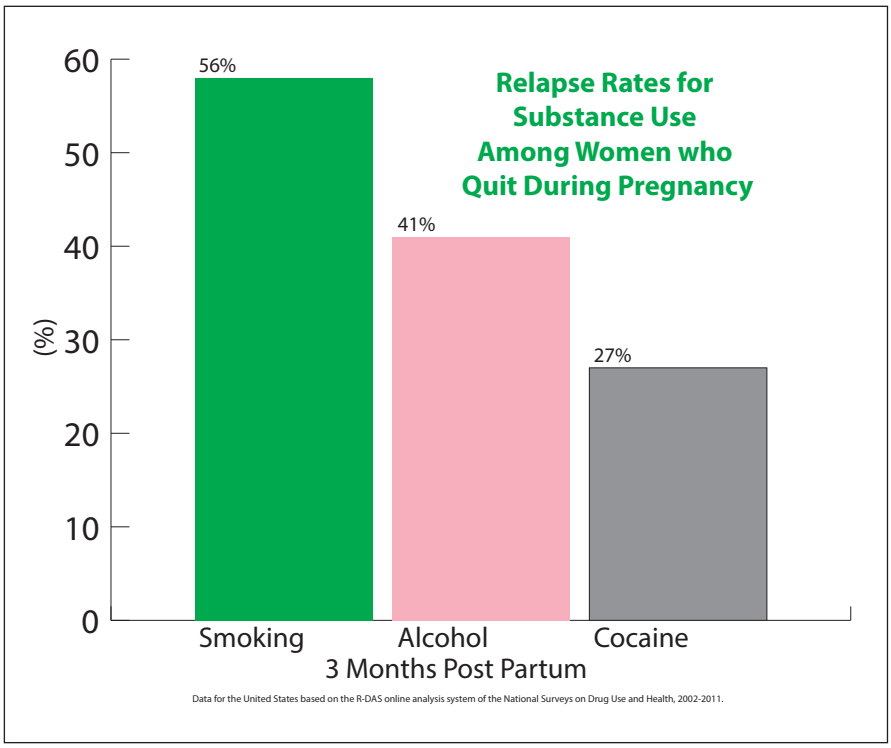
This data demonstrates the need for a systematic approach to screening for prenatal alcohol exposure during prenatal care, after delivery, and during well child care.

North Dakota had
3,400 women using alcohol
during pregnancy in 2017

Heavy users who drink
all 40 weeks of pregnancy = 162

After birth, relapse is common.

Many women who quit drinking, smoking, or using drugs during pregnancy begin again right after the birth of the baby. The importance of screening during well child care is demonstrated by the following data. Early detection provides an opportunity to prevent exposure in a subsequent pregnancy by use of office based interventions.



Drinking while breastfeeding.

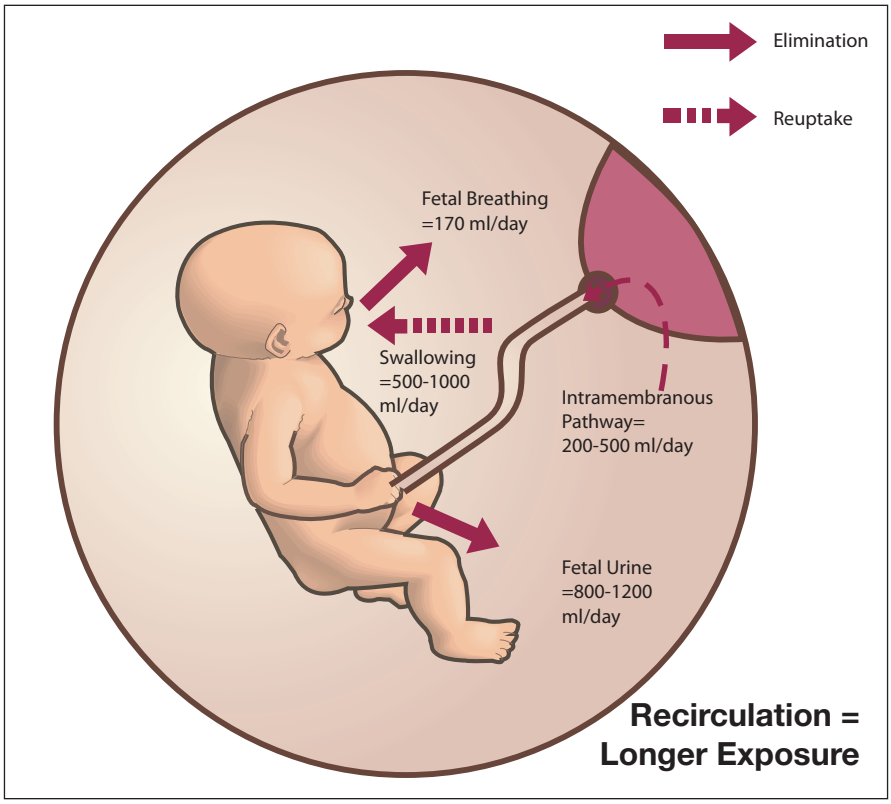
Among women who drank and breastfed (71%), alcohol use was associated with increased rates of neurobehavioral impairments and growth deficits. Drinking while breastfeeding is not recommended (May et al., 2016).

Prenatal substance exposure increases the risk for adverse outcomes for the fetus by three fold.

(Lamy et al., 2016).

Mechanisms of Exposure Differ by Gestational Age.

Pathways of ethanol entry and removal from the fetal compartment and amniotic fluid change as pregnancy progresses.

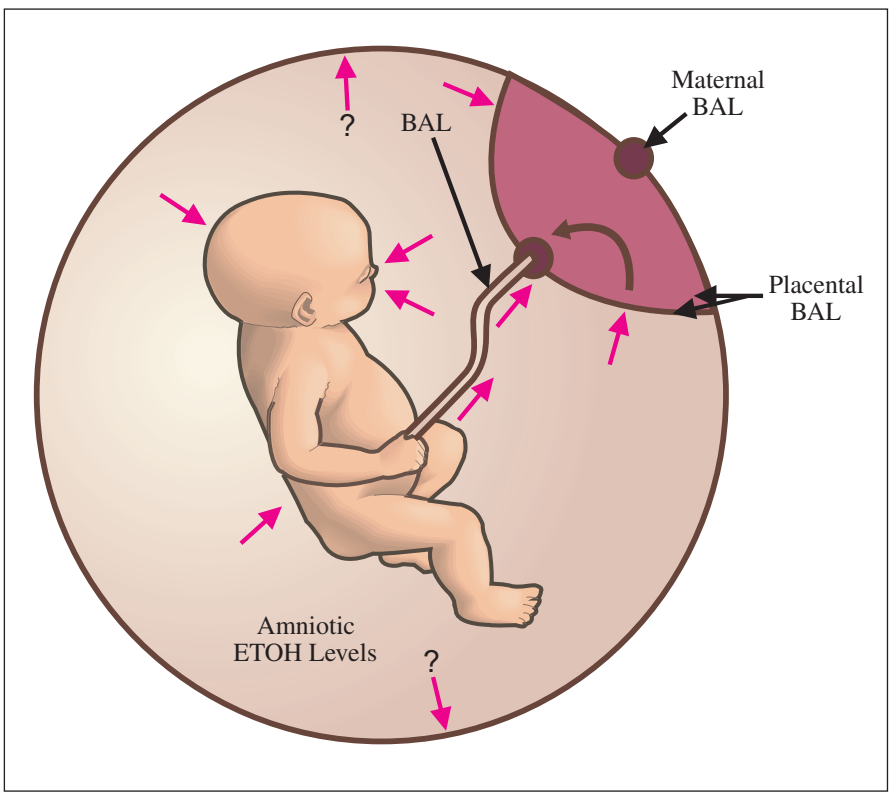


Importantly, exposure is multigenerational.

When a pregnant woman drinks she exposes herself, the fetus and the fetal germline.

The physiology of fetal alcohol exposure changes across gestation.

Early in pregnancy placental, fetal, and amniotic fluid concentrations of alcohol exposure are equivalent. Beginning in mid-pregnancy, the maturing fetal epidermis adds keratins which decrease permeability resulting in development of a barrier between fetal circulation and the amniotic fluid. By 30 gestational weeks, development of barrier function alters the pathophysiology of ethanol dispersion between the fetus and amniotic fluid. Firstly, increases in the effectiveness of barrier function decreases the rate of diffusion of alcohol from fetal circulation across fetal skin into the amniotic fluid. This reduces the volume of alcohol entering the amniotic fluid. Secondly, fetal barrier function increases the duration of fetal exposure by decreasing the rate of alcohol diffusion from amniotic fluid back into fetal circulation (Longhurst et al., 2016). Ethanol is then transported into maternal circulation for metabolism or elimination. This increases the duration of exposure from each episode of drinking.



FASD: What about the men?

Prenatal Alcohol Exposure

Increased risk of impotence 8%[1]

Lack of sexual desire increased 31% to 58%[2]

Double the risk of erictile dysfunction[3]

Decreased sperm (volume, motility, and abnormal sperm)[4,5]

Increase in risk of miscarriage 2-15 times[6]

Women drink with partner over 75% of the time[7]

Drinking is initiated by man over 40% of the time[7]

Increased risk of fetal death[6, 8]

Decreased birth weight[9]

Late start to prenatal care[10]

Fewer prenatal visits[10]

1. Lemere et al 1973 Am J Psychiat 130: 212-213; 2. Whalley et al 1978: Acta Psychiat Scand 58: 281-298; 3. Jensen SB 1984: Acta Psychiat Scand 69: 543-549; 4. Gumus et al 1998: Int Urol Nephrol: 30 755-759; 5. Muthusami et al 2005: Fertility adn Sterility 84: 918-924; 6. Henriksen et al 2004; Am J Epidemiol: 160 661; 7. McBride et al 2012: Global Health Promotion 19: 102-114; 8. Muthusami et al 2005: Fertility and Sterility 84: 918-924; 9. LIttle et al 1987: Teratology 36: 59-65; 10. Burd et al 2003: Neurotoxicoloty and Teratology: 25(6) 681-688.

Polysubstance Abuse Increases Risks.

In substance abuse additional risks produce multiplicative risk enhancement especially for polysubstance abuse. This demonstrates the potential effect of risk reduction by reducing the multiplicative effects from each risk marker.

Increased Risk for Fetal Alcohol Spectrum Disorders From Combined Exposures

15% Risk Interactions 15%

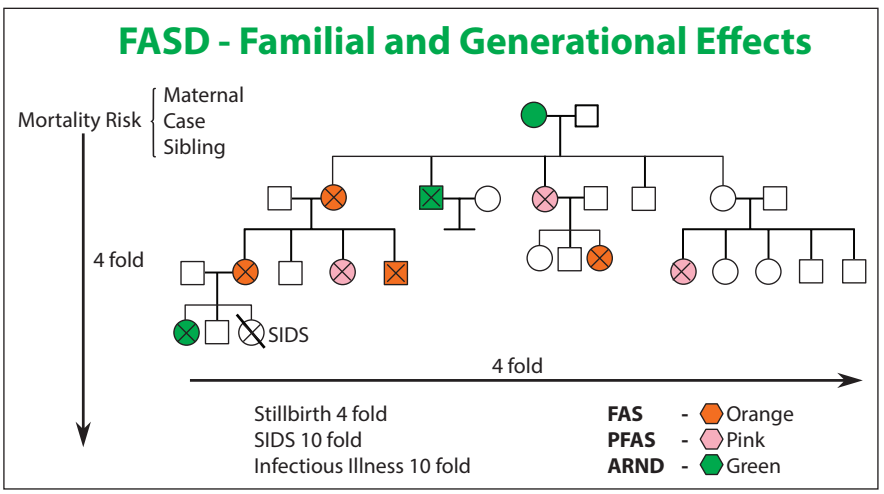
Additive = 30%

Multiplicative = 46%

Odendall et al., 2009, Gynec & Obstet Invest

Exposure is often generational and familial.

In North Dakota sequela of prenatal alcohol exposure increases over generations and within sib ships.



Detection of Prenatal Alcohol Exposure

We have well developed detection programs for prenatal alcohol exposure in North Dakota where over 90% of pregnancies have at least one systematic screen during pregnancy. We utilize the One-Question Screen.

Exposure Assessment — **How We Do It**

Exposure

When was your last drink?

Risk Stratfication

Before	Pregnancy	
	Pre-awareness	Post-awareness
Unexposed	Exposed	Exposed & High Risk

Dosimetry

Charting PAE 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)

What is a drink? Alcohol % ____ Drink vol ____

When a history of prenatal alcohol exposure is not available, we use the Maternal Risk Score for exposure risk stratification.

Estimating Exposure Risk

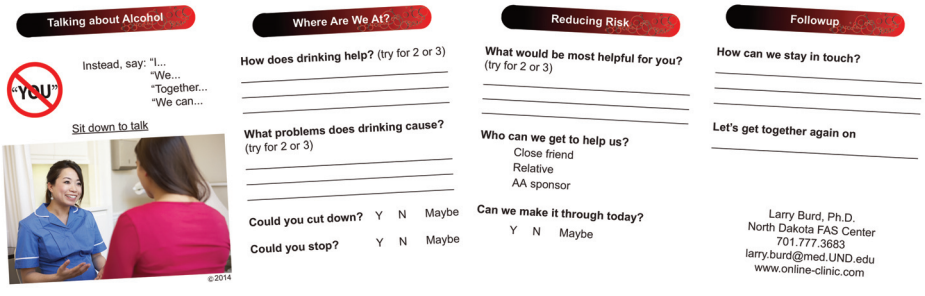
Maternal Risk Score

			Score
_____	Age over 25 years		
_____	Unmarried, divorced, widow, living with partner		
_____	On TANF, WIC, Social Security or income < $16,000 per year		
_____	Did not graduate from high school		
_____	Poor diet	Check Any One Add 5	_____
_____	Smokes more than 1/2 pack per day		
_____	Drinks, but less than 2 days/week & less than 2 drinks /drinking day	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 died		
_____	Previous child with FASD, or developmental disability		
_____	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)		
_____	Uses inhalants, sniffs or illegal drugs	Check Any One Add 45	
			_____

Score	Risk Category	Recommendations
0	None	Standard prenatal care
5	Low	Standard prenatal care
20-40	Moderate	Standard Prenatal care and FASD education
45-50	High	High risk pregnancy, alcohol-drug abuse treatment
55-105	Very High	High risk pregnancy, alcohol-drug abuse treatment

Total Score ☐

We have recently added an in-office intervention strategy for prenatal care providers in North Dakota. Training across all prenatal care sites is ongoing.



Prenatal alcohol exposure predicts increase in risk for adverse outcomes.

Ideal screening opportunities are:

Prior to pregnancy
At the first prenatal visit
During pregnancy
At delivery
During at least one well child visit

Screening for prenatal alcohol should be multi-tiered. Screeners need training to be even modestly effective.

How common is fetal alcohol spectrum disorder (FASD)?

1-5% of all live births
In North Dakota we have 11,000 births each year, So we have between 110-550 affected babies born each year. Only 5-15% will ever be diagnosed with FASD. Nearly 90% will never be treated for FASD.

A snapshot of FASD in North Dakota

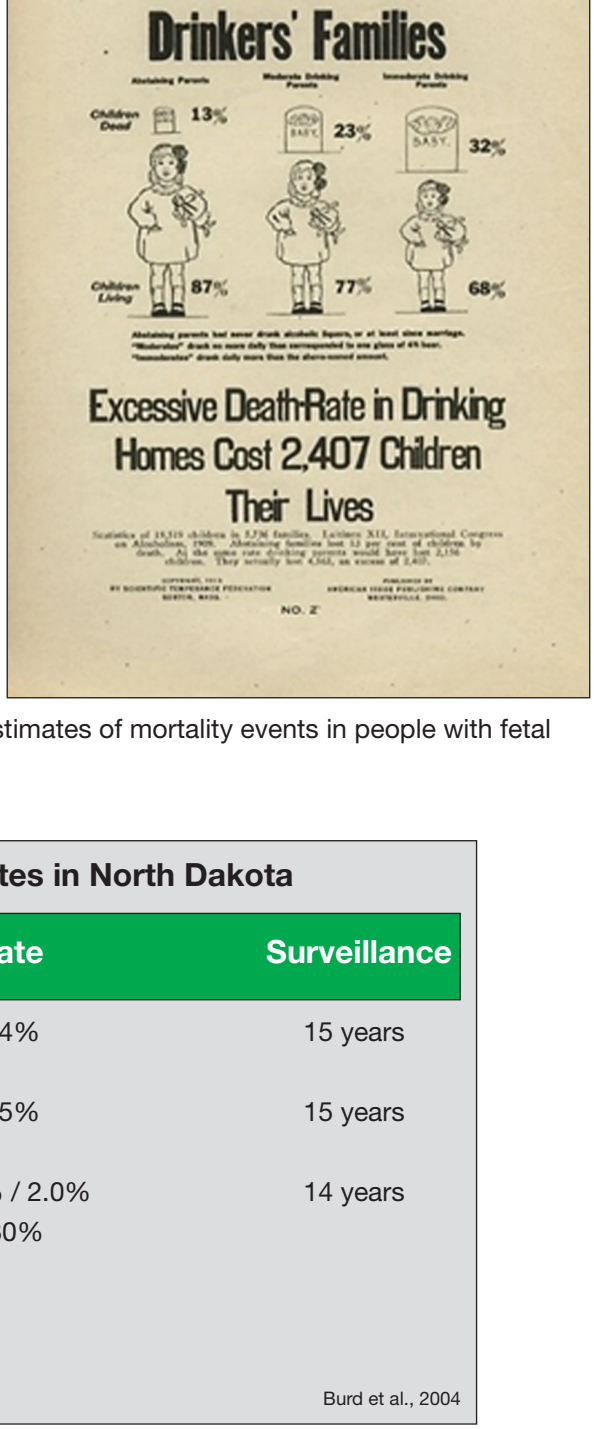
New cases born each year 110-550
Annual cost for new cases (330 cases = $7.5 million)
Birth - 18 years of age cohort (1,980-9900)

As a comparison for every case of neonatal abstinence syndrome we have 7-35 cases of FASD in North Dakota

[1] Greenmeyer et al 2018.

Prenatal alcohol exposure increases mortality risk.

Mortality in clinical settings often occurs before a diagnosis of prenatal alcohol exposure or fetal alcohol spectrum disorder is diagnosed. Thus, mortality estimates in clinical settings are often very low. Alcohol exposure has been a cause of concern for increased mortality for over 100 years.



However, in North Dakota we have excellent estimates of mortality events in people with fetal alcohol spectrum disorder.

FASD Mortality Rates in North Dakota

Population	Rate	Surveillance
FASD	5.4%	15 years
Maternal	4.5%	15 years
Sibling	11.4% / 2.0% 530%	14 years

- Infectious OR 13.7
- SIDS OR 10.2

Burd et al., 2004

Mortality Publications

Thompson, A., Hackman, D., & Burd, L. Mortality in fetal alcohol spectrum disorders. *Open Journal of Pediatrics* 2014, 4(1), 21-33.

Burd, L., Peterson, L., & Kobrinsky, N. Fetal Alcohol Spectrum Disorders and Childhood Cancer: A Concise Review of Case Reports and Future Research Considerations. *Pediatr Blood Cancer* 2013, doi: 10.1002/pbc.24886

Burd, L., Klug, M.G., Bueling, R., Martsolf, J., Olson, M., & Kerbeshian, J. Mortality Rates in Subjects with Fetal Alcohol Spectrum Disorders and Their Siblings. *Birth Defects Research (Part A)* 2008, 82(4), 217-223.

Eaglestaff, M.L., Klug, M.G., & Burd, L. Eight Years of Infant Mortality Reviews in the Aberdeen Area of the Indian Health Service. *The IHS Provider* June 2007, 174-180.

Eaglestaff, M.L., Klug, M.G., & Burd, L. Infant Mortality Reviews in the AAIHS: Strategies and Outcomes. *Public Health Reports* 2006, 121(2), 140-148.

Burd, L., Klug, M.G., & Martsolf, J.T. Increased Sibling Mortality in Children with Fetal Alcohol Syndrome. *Addiction Biology* 2004, 9, 179-186.

Burd, L., & Wilson, H. Fetal, Infant, and Child Mortality in a Context of Alcohol Use. *American Journal of Medical Genetics Part C* (Semin. Med. Genet.) 2004, 127C, 51-58.

Maternal mortality is hugely increased in mothers of children who have been diagnosed with a fetal alcohol spectrum disorder.

Fetal alcohol spectrum disorders (FASD) are associated with an increase in risk for mortality for people with an FASD and their siblings. In this study we examine mortality rates of birth mothers of children with FASD, using a retrospective case control methodology. We utilized the North Dakota FASD Registry to locate birth certificates for children with FASD which we used to identify birth mothers. We then searched for mothers' death certificates. We then compared the mortality rates of the birth mothers with an age matched control group comprised of all North Dakota women who were born and died in the same year as the birth mother. The birth mothers of children with FASD had a mortality rate of 15/304 = 4.93%; (95% CI 2.44-7.43%). The mortality rate for control mothers born in same years as the FASD mothers was 126/114,714 = 0.11% (95% CI 0.09-0.13%). Mothers of children with an FASD had a 44.82 fold increase in mortality risk and 87% of the deaths occurred in women under the age of 50. Three causes of death (cancer, injuries, and alcohol related disease) accounted for 67% of the deaths in the mothers of children with FASD. A diagnosis of FASD is an important risk marker for premature death in the mothers of children diagnosed with an FASD. These women should be encouraged to enter substance abuse treatment (Li et al., 2012).

Summary of the North Dakota FASD Family

THE DADS

Age	30.8
Education	10.9
Unmarried	63%
Alcoholic	12+years
Heavy Drinker	+
Treatment	<3
Low SES	+

THE MOMS

Age	27.4
Education	10.6
Unmarried	63%
Smoker	82%
Alcoholic	10+years
Treatment	>3 (45%)
Low SES	+
Poor Diet	+
Parity	3
Prenatal Visits	<5 (56%)
1st Prenatal	>1st tri (56%)
Mortality	4.9%

Previous Terminations	↑
Number of Prenatal Visits	↓
Number of Prenatal Complications	↑
Birth Weight	↓

THE CHILDREN

Age Diagnosis	7.1 Years
Older Sibs	2
Younger	2
Mean Birth Weight	-701 grams
Birth Defects	15%
Cerebral Palsy	6%
Intellectual Disability	20%
ADHD	75%
Out of Home	85%
Head Injury	15%
If FASD Diagnosis	1 dead sibling (9%)
	2 dead siblings (2%)
	3 dead siblings (5%)

Mortality

FASD Mothers	=	4.9%
Controls	=	0.11%
OR	=	44.82

50% died by age 41.5

87% died by age 50

- Cancer
- Alcohol Related — 67%
- Accidents

31.3 YPLL per case

Mortality Rate

FASD	=	5.4%
FASD Sibling	=	11.4%
Sibling Controls	=	2.0%
RR	=	530%
Infection OR	=	13.7
SIDS OR	=	10.2

Number of Prenatal Complications	↑
Number of Prenatal Visits	↓
Late Start Prenatal Care	↑
Birth Weight	↓
Number of Malformations	↑

Burd, L., Klug, M.G., Martsolf, J.T., & Kerbeshian, J. Fetal Alcohol Syndrome: Neuropsychiatric Phenomics. *Neurotoxicology and Teratology* 2003, 25(6), 697- 705

Prevalence of fetal alcohol spectrum disorder in North Dakota

FASD in North Dakota

- 1% of live births
- 20% recurrence risk
- More severe in younger siblings
- 5% ever diagnosed
- Increasing rates of neuropsychiatric disorders

Fetal Alcohol Spectrum Disorder North Dakota, 2013

Deliveries	10,591
FASD (1%)	105
Children birth-18	1,890
FASD recurrent (20%)	21
North Dakota Diagnosed	795

FASD is more prevalent than Down Syndrome, muscular dystrophy, or autism spectrum disorder.

What does FASD cost?

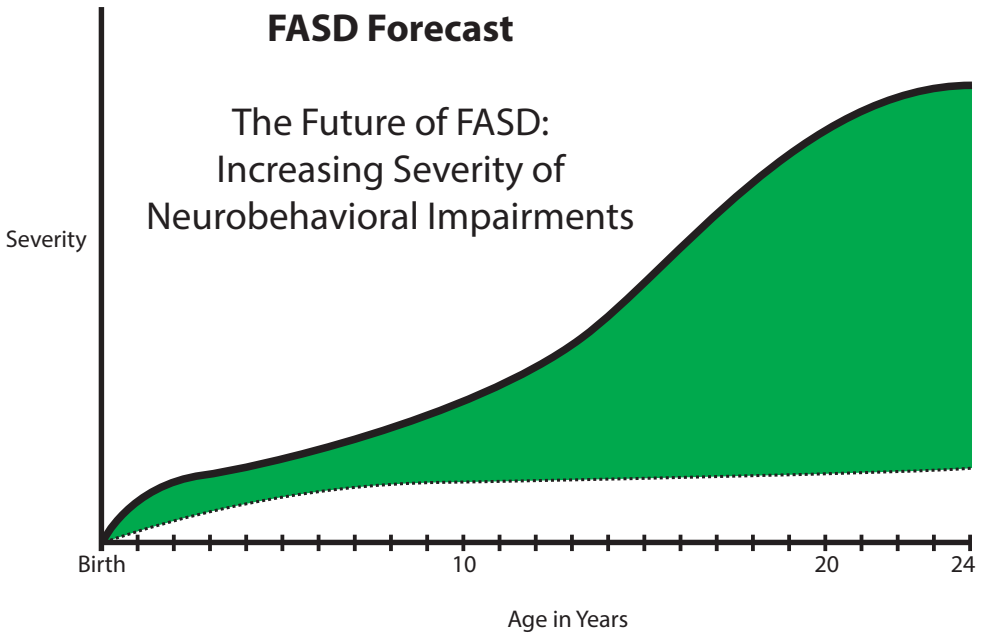
On average we hit the million dollar cost of care for FASD at age 43 years.[1]

The annual cost for FASD worldwide is $22,810/year for children. Thus each year we spend an extra $22,810/child with FASD. By 21 years of age we have spent $479,010. For adults the annual cost is $24,308, so by age 40 we will have spent another $461,852.

[1] Greenmyer, J.R., Klug, M.G., Kambeitz, C., Popova, S., Burd, L. A multicountry updated assessment of the economic impact of fetal alcohol spectrum disorder: Costs for children and adults, J Addict Med, 12(6), November/December, 2018.

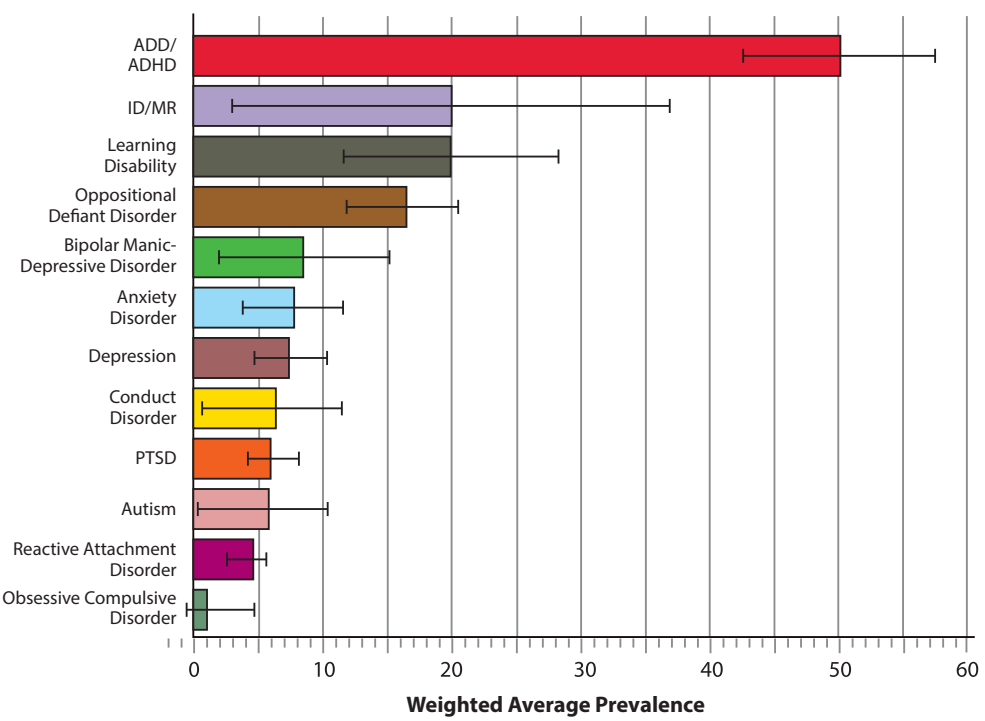
FASD becomes more complex over time.

(Burd, L. Fetal alcohol spectrum disorder: Complexity from comorbidity. Lancet, vol 387, March 5, 2016)



FASD is a huge risk enhancer for developmental disorders and mental illness

Figure 1. Percentage of Disorders Comorbid With FASD (1981-2015) (n=5,618)



Incarceration Risk for FASD

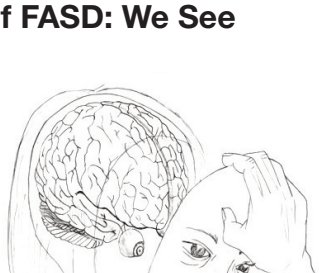
- In Canada youth 12-18 years of age with FASD have a 19 fold increase risk of incarceration.

  Popova L., Am J Epidemiol, 2012

Nearly all FASD is Alcohol Related Neurodevelopmental Disorder and not Fetal Alcohol Syndrome.

Behind the Face of FASD: We See

- ADHD
- Depression
- Cognitive Impairment
- Intellectual Disability
- Learning Disabilities
- Substance Abuse
- Judgment Deficits



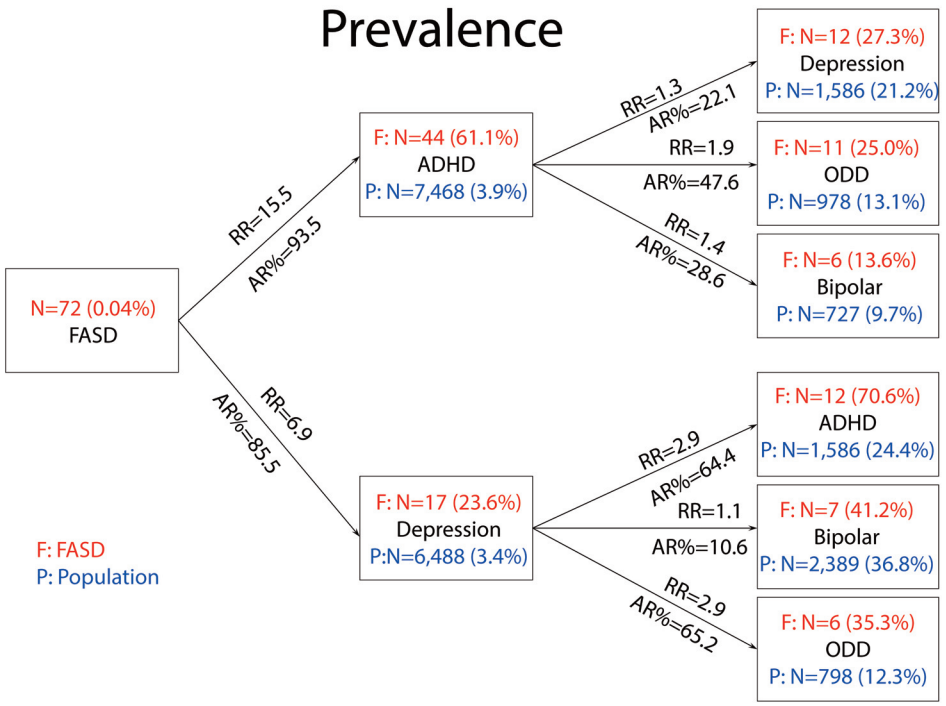
Most children with FASD are in out-of-home foster care system.

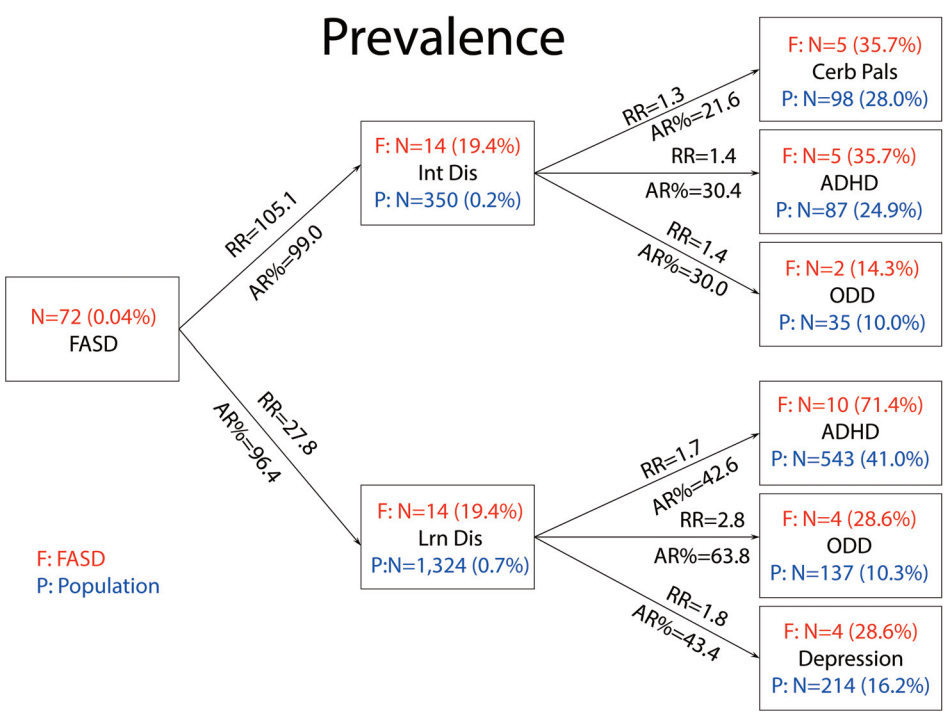
Foster Care Placement in Children (Birth - 18 Years of Age)

- FAS: 336
- ARND: 1344
- Total FASD: 1680
- Years of Foster Care: 768

Several hundred hours of foster care are required every year for children with FASD in North Dakota.

FASD is a large and enduring risk enhancer for development of mental disorders and developmental disabilities.





The costs for health care, mental health are greatly increased for children with FASD.

Fetal alcohol syndrome (FASD) is a common developmental disability. FASD is thought to be 100% preventable. While this is a theoretical truth, a prevention rate of 100% appears unlikely in the near future. However, several prevention strategies are available. In this paper, we examine the potential cost savings from prevention of one case of FASD each year in the state of North Dakota. We utilized the North Dakota Health Claims Database to examine annual cost of health care for children birth through 21 years of age with FASD and controls. The mean annual cost of health care for children birth through 21 years of age with FASD was $2842 (n = 45). This is $2342 per capita more than the annual average cost of care for children in North Dakota who do not have FASD ($500 per year).

Prevention of one case of FASD per year in North Dakota would result in a cost savings of $128,810 in 10 years and $491,820 after 20 years. After 10 years of prevention, the annual savings in health care costs alone for one case of FASD would be $23,420 (Klug & Burd, 2003).

Popova et al have completed a series of cost of care estimates for FASD in Canada that are likely to be useful in North Dakota.

Popova, S., Lange, S., Burd, L., & Rehm, J. Health care burden and cost associated with fetal alcohol syndome: Based on official Canadian data. PloS ONE, 2012, Aug. 7(8) e43024 doi:10.1371/journal.pone.0043024.t004.

Popova, S., Lange, S., Burd, L., Urbanoski, K., & Rehm, J. Cost of specialized addiction treatment of clients with fetal alcohol spectrum disorder in Canada. BMC Public Health 2013, 13(6) 570. http://www.biomedcentral.com/1471-2458/13/570

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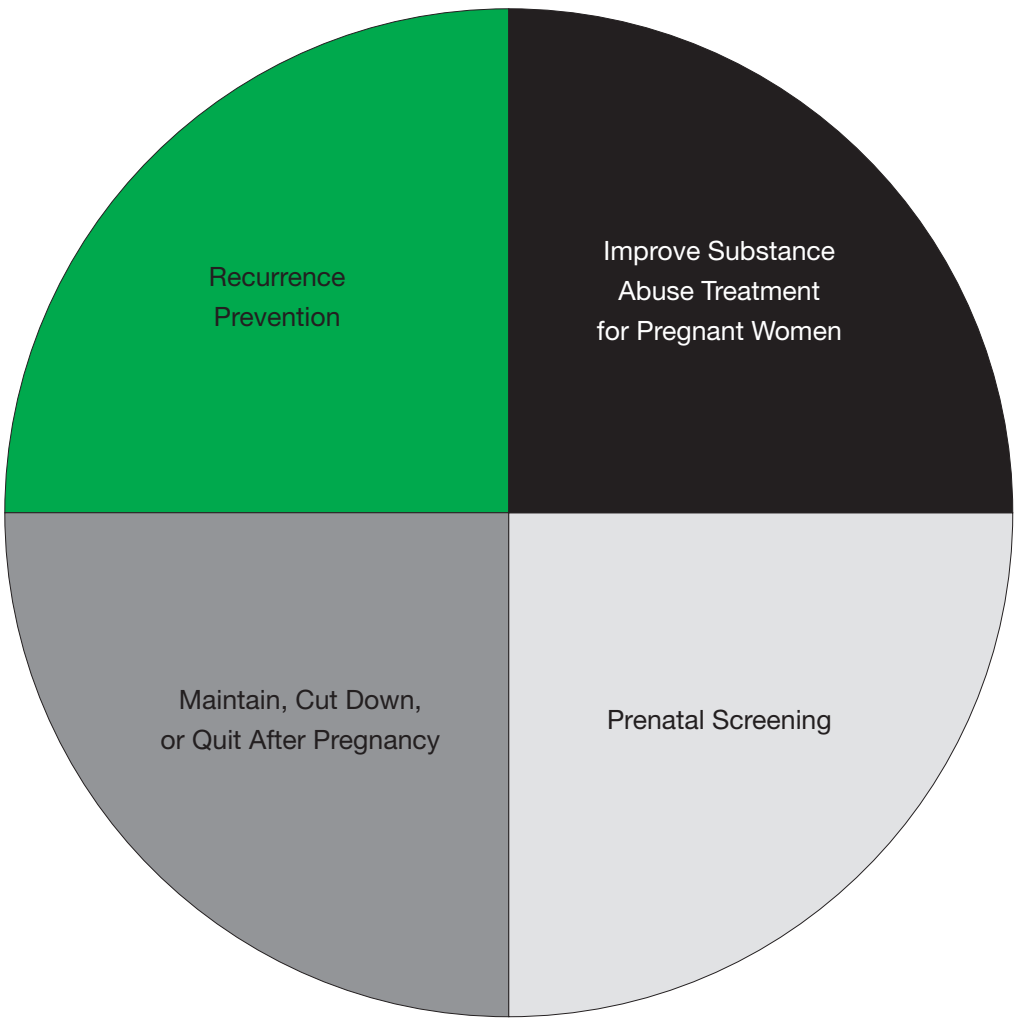
Popova, S., Lange, S., Burd, L., Nam, S., & Rehm, J. (2016). Special education of children with Fetal Alcohol Spectrum Disorder. *The Exceptionality*. Published online March 23. From http://dx.doi.org/10.1080/09362835.2015.1064415.

Prevention strategies for prenatal alcohol exposure and FASD in North Dakota. (Always Reduce Smoking).



Prevention of fetal alcohol spectrum disorder is one of the most effective strategies for reducing the cost of health care, foster care, special education, juvenile justice, developmental disabilities, substance abuse treatment, and in the corrections system.

This table models cost of prevention by risk level using alcohol treatment as the intervention when treatment 50% effective.

Alcohol Use & Other Risk Factors	Risk of FASD	Women Treated	Women Quit[a]	Cases Prevented	Cost Per Case Prevented
Daily alcohol use	0.01%	20,100	10,000	1	$100,000,000
Heavy Drinkers, middle class, non-smokers	.29%	690	344	1	3,450,000
Heavy drinkers, low income, smokers, poor diet	4.3%	47	23	1	235,000
Women who have had a previous child with FASD	75.0%	3	1	1	15,000

Additional information and more detailed modeling data are available at: http://www.online-clinic.com on FASD Exposure Model.

[a]Quit after 1 year.

2021 HOUSE STANDING COMMITTEE MINUTES

Human Services Committee
Pioneer Room, State Capitol

HCR 3011
1/18/2021

A concurrent resolution directing the Legislative Management to consider studying fetal alcohol spectrum disorders (FASDs), including treatment, services available, potential prevention, and whether existing policies are appropriate.

Chairman Weisz opened the hearing at 3:04 p.m.

Representatives	Roll Call
Representative Robin Weisz	P
Representative Karen M. Rohr	P
Representative Mike Beltz	P
Representative Chuck Damschen	P
Representative Bill Devlin	P
Representative Gretchen Dobervich	P
Representative Clayton Fegley	P
Representative Dwight Kiefert	P
Representative Todd Porter	P
Representative Matthew Ruby	P
Representative Mary Schneider	P
Representative Kathy Skroch	P
Representative Bill Tveit	P
Representative Greg Westlind	P

Discussion Topics:

- Specific language studying adults living in North Dakota with fetal alcohol syndrome
- Ensuring we have appropriate services in place when needed
- After policies insert “for children and adults.”

Rep. Gretchen Dobervich moved **Amendment 21.3021.01001**.

Rep. Kathy Skroch second

Voice Vote – Motion Carried

Rep. Matthew Ruby moved **Do Pass as Amended.**

Rep. Mary Schneider second

Representatives	Vote
Representative Robin Weisz	Y
Representative Karen M. Rohr	Y
Representative Mike Beltz	Y

Representative Chuck Damschen	Y
Representative Bill Devlin	Y
Representative Gretchen Dobervich	Y
Representative Clayton Fegley	Y
Representative Dwight Kiefert	Y
Representative Todd Porter	Y
Representative Matthew Ruby	Y
Representative Mary Schneider	Y
Representative Kathy Skroch	Y
Representative Bill Tveit	Y
Representative Greg Westlind	Y

Motion Carried Do Pass As Amended 14-0-0

Bill Carrier: Rep. Mary Schneider

Chairman Weisz adjourned at 3:11 p.m.

Tamara Krause, Committee Clerk

21.3021.01001
Title.02000

Adopted by the Human Services Committee

January 18, 2021

1/18/21

PROPOSED AMENDMENTS TO HOUSE CONCURRENT RESOLUTION NO. 3011

Page 1, line 3, after "policies" insert "for children and adults"

Page 2, line 2, after "policies" insert "for children and adults"

Renumber accordingly

REPORT OF STANDING COMMITTEE

HCR 3011: Human Services Committee (Rep. Weisz, Chairman) recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** and **BE PLACED ON THE CONSENT CALENDAR** (14 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). HCR 3011 was placed on the Sixth order on the calendar.

Page 1, line 3, after "policies" insert "for children and adults"

Page 2, line 2, after "policies" insert "for children and adults"

Renumber accordingly

2021 SENATE HUMAN SERVICES

HCR 3011

2021 SENATE STANDING COMMITTEE MINUTES

Human Services Committee
Sakakawea Room, State Capitol

HCR 3011
3/29/2021

A concurrent resolution directing the Legislative Management to consider studying fetal alcohol spectrum disorders (FASDs), including treatment, services available, potential prevention, and whether existing policies for children and adults are appropriate.

Madam Chair Lee opened the hearing on HCR 3011 at 10:50 a.m. Members present: Lee, K. Roers, Hogan, Anderson, Clemens, O. Larsen.

Discussion Topics:

- Parenting challenges
- FASD behavioral symptoms

[10:51] Representative Bernie Satrom, District 12. Introduced HCR 3011.

[10:57] Carl Young, Lobbyist, Executive Director, Family Services Network. Provided testimony #10892 in favor as well as Fetal Alcohol Spectrum Disorder documents (testimony #10893, #10894, #10895, and #10896).

[11:01] Jerry Bloemendaal, Jamestown Resident. Provided oral testimony in favor.

Additional written testimony: (1)

Dr. Larry Burd, Professor, Department of Pediatrics, UND School of Medicine and Health Services. Written testimony #10859 in favor and provided a Report on Fetal Alcohol Exposure and Fetal Alcohol Spectrum Disorders (testimony #10858).

Madam Chair Lee closed the hearing on HCR 3011 at 11:13 a.m.

Justin Velez, Committee Clerk

Carl Young
Family Services Network Inc.
Executive Director
Lobbyist Badge Number 136
Bismarck, ND 58504
7012143152
carl@ndctn.org

March 29, 2021

Chair Lee, members of the committee. My name is Carl Young. I am the Executive Director of the Family Services Network, Inc. here in Bismarck. We are the statewide affiliate for the National Organization on Fetal Alcohol Syndrome (NOFAS). My wife and I established the organization in 2018 after our son had been removed for the last time from our home for attacking us.

Our son, born in 2001, was diagnosed in 2016 with Fetal Alcohol at the University of North Dakota Fetal Alcohol Clinic. If we had known in the beginning what he was faced with, his whole world might be different. Not to say we would not have had frequent issues requiring out of home placement. But that we could have fought a different fight for him, and for the rest of our family.

Fetal Alcohol Syndrome affects not just the person afflicted with the disorder, but everyone that person encounters. In our family, it meant frequent attacks on me. It meant 10 out of home placements over 10 years. It meant that once ahe turned 18, thru his own choices, he was basically homeless.

It means that he is facing a possible lifetime of criminal activity. He has accrued more than 15 charges in 2 years, some requiring significant jail time. His most recent incident resulted in him spending 4 months in jail, for an incident that could have resulted in 4 to 10 years in prison. An incident that involved firearms and a series of shots exchanged with law enforcement.

Our son has zero impulse control. None. He does not think before he does. This is because one of the areas significantly impacted by FAS is the frontal lobe. Where impulse control resides in an area of the brain that controls executive function.

I stand in support of HCR3011. I have uploaded both this testimony and several handouts.

I will allow others to present their story and stand for any questions.

On March 20, 2021, I helped my son move to Fargo, to a residence with the F5 Project with the hope that a fresh start in a different city will help him be the person I know he can be. It was his choice to make the move. He knows he does not like jail. He knows he is easily influenced. He is at a loss as to how to change that.

Thank you
Carl Young

#10893

Overlapping Behavioral Characteristics & Related Mental Health Diagnoses in Children

Overlapping Characteristics & Mental Health Diagnoses	FASD	ADD/ ADHD	Sensory Int. Dys.	Autism	Bi-Polar	RAD	Depres-sion	ODD	Trauma	Poverty
	Organic	Organic	Organic	Organic	Mood	Mood	Mood	Mood	Environ	Environ
Easily distracted by extraneous stimuli	X	X								
Developmental Dysmaturity	X			X						
Feel Different from other people	X				X					
Often does not follow through on instructions	X	X					X	X	X	X
Often interrupts/intrudes	X	X	X	X	X		X			X
Often engages in activities without considering possible consequences	X	X	X	X	X					X
Often has difficulty organizing tasks & activities	X	X		X	X		X			X
Difficulty with transitions	X		X	X	X					
No impulse controls, acts hyperactive	X	X	X		X	X				
Sleep Disturbance	X				X		X		X	
Indiscriminately affectionate with strangers	X		X		X	X				
Lack of eye contact	X		X	X		X	X			
Not cuddly	X			X		X	X			
Lying about the obvious	X				X	X				
Learning lags: "Won't learn, some can't learn"	X		X			X			X	X
Incessant chatter, **or** abnormal speech patterns	X		X	X	X	X				
Increased startle response	X		X						X	
Emotionally volatile, often exhibit wide mood swings	X	X	X	X	X	X	X	X	X	
Depression develops, often in teen years	X	X				X			X	
Problems with social interactions	X			X	X		X			
Defect in speech and language, delays	X			X						
Over/under-responsive to stimuli	X	X	X	X						
Perseveration, inflexibility	X			X	X					
Escalation in response to stress	X		X	X	X		X		X	
Poor problem solving	X			X	X		X			
Difficulty seeing cause & effect	X			X						
Exceptional abilities in one area	X			X						
Guess at what "normal" is	X			X						
Lie when it would be easy to tell the truth	X				X	X				
Difficulty initiating, following through	X	X			X		X			
Difficulty with relationships	X		X	X	X	X	X			
Manage time poorly/lack of comprehension of time	X	X			X		X			X
Information processing difficulties speech/language: receptive vs. expressive	X			X						
Often loses temper	X		X		X		X	X	X	
Often argues with adults	X				X			X		
Often actively defies or refuses to comply	X				X			X		
Often blames others for his or her mistakes	X	X			X		X	X		
Is often touchy or easily annoyed by others	X				X		X	X		
Is often angry and resentful	X						X	X		

Cathy Bruer-Thompson, retired, Minnesota Organization on Fetal Alcohol Syndrome Board Vice-President, Special Needs Adoption Trainer cathybt@gmail.com 4/29/2016

With deep appreciation to the many who edited and contributed
www.mofas.org

References and Resources for

"Overlapping Behavioral Characteristics and Related Mental Health Diagnoses in Children"

Diane Malbin: Clinical social worker, program developer, nationally recognized trainer on FASD and consultant, co-founder of FASCETS (Fetal Alcohol Syndrome Consultation)

MOFAS (Minnesota Organization on Fetal Alcohol Syndrome): www.mofas.org

NAMI: National Alliance on Mental Illness - factsheets on mental health diagnoses, characteristics, medications, resources, local support groups for many mental illnesses

http://www.nami.org/Template.cfm?Section=By_Illness

- Attention Deficit Hyperactivity Disorder
- Autism Spectrum Disorder
- Bi-Polar Disorder
- Reactive Attachment Disorder
- Obsessive-Compulsive Disorder
- Post Traumatic Stress Disorder

Bruce D. Perry, M.D., Ph.D.: Senior Fellow of *The ChildTrauma Academy*

His neuroscience research has examined the effects of prenatal drug exposure on brain development, the neurobiology of human neuropsychiatric disorders, the neurophysiology of traumatic life events and basic mechanisms related to the development of neurotransmitter receptors in the brain.

Bessel van der Kolk, MD: clinician, researcher and teacher in the area of posttraumatic stress and related phenomena, Medical Director of *The Trauma Center,* a program of Justice Resource Institute

"Developmental Trauma Disorder: A New Rational Diagnosis for Children With Complex Trauma Histories," by Bessel van der Kolk, Psychiatric Annals, May 2005.

"Complex Trauma in Children and Adolescents," Cook, Spinazzola, Ford, Lanktree, Blaustein, Cloitre, DeRosa, Hubbard, Kagan, Mallah, Olafson, van der Kolk, 2005, Psychiatric Annals, pp. 390-398- Psychiatric Annals, May 2005.

Also "Attachment, Self-regulation and Competency (ARC)"

Mayo Clinic: Reactive Attachment Disorder Symptoms

http://www.mayoclinic.com/health/reactive-attachment-disorder/DS00988/DSECTION=symptoms

Walter D. Buenning, PhD, Licensed Psychologist

Reactive Attachment Disorder Child Checklist of Characteristics
http://www.reactiveattachmentdisordertreatment.com/childattachchecklist.pdf

Ruby K. Payne, Ph.D.: *A Framework for Understanding Poverty* and *Bridges Out of Poverty*

Research focuses on the effects of poverty on students, families, and communities and how to better understand and support people from all economic backgrounds

In addition this document was reviewed for accuracy by several Minnesota experts in Children's Mental Health and Fetal Alcohol Spectrum Disorders

Understanding Behaviors of Fetal Alcohol Spectrum Disorders (FASD)

PR%F Alliance

Won't...or can't?

Without an understanding of the physical, behavioral and cognitive challenges faced by people with fetal alcohol spectrum disorders (FASD), typical misbehaviors can be misinterpreted as intentional misconduct or deliberate disobedience, when it is often just the opposite. When it seems like your child won't do something, it might be that they can't do it – at least not without support.[1] Remember that everyone with an FASD has the ability to succeed. Strategies, support, and interventions can help reduce the long-term effects of prenatal alcohol exposure and improve outcomes, behavior, and well-being for people with an FASD.[2]

Domains impacted by prenatal alcohol exposure

Due to the brain injury caused by prenatal alcohol exposure, people with an FASD may have difficulty with the following:[3-7]

Sensory processing: They may have issues processing sensory information, such as touch, sound, or movement. This can lead to overstimulation and anxiety, aggressive behavior, or inability to learn or perform.

Cognitive skills: This can include learning difficulties, poor impulse control, and issues with memory and attention.

Abstract reasoning: If the frontal lobe has been affected by prenatal alcohol exposure, abstract reasoning can be difficult for the brain to process. Instead, be concrete and speak in literal terms. When giving directions, provide them step-by-step in detail.

Cause and effect reasoning: Remembering consequences can often be difficult due to impulsivity and memory issues. Because of this, consequences often will not shape future behavior for people with an FASD.

Generalization: What is understood or done in one setting does not automatically transfer to similar settings. Be aware that if you change one part of the person's routine, you have created an entirely new routine and this can require some adjustment.

Hyperactivity: This can include difficulty staying focused, being easily distracted, and having issues self-regulating when they are overstimulated or tired.

Memory: People with prenatal alcohol exposure often have issues with memory, especially working memory. Visual memory is often better. "Show" them, rather than "tell" them. Use fewer words. Understand that at times, a person with an FASD may not be able to complete a task that they had successfully completed many times before.

Adaptive functioning: People with an FASD might have issues with functioning independently and developing and maintain daily living skills.

Understanding Behaviors of Fetal Alcohol Spectrum Disorders (FASD)

PR%F Alliance

Secondary Characteristics

FASD is a lifelong disability, and "secondary characteristics" can occur as a result of living with the struggles associated with prenatal alcohol exposure. Secondary characteristics can include:[8-11]

- Fatigue
- Tantrums
- Irritability, frustration, and/or anxiety
- Avoidance, withdrawal, being shut down, lying, and/or running away
- Trouble at home and/or school
- Legal trouble, drug/alcohol abuse
- Mental health issues

The impact of these secondary conditions can be reduced when caregivers and professionals understand the challenges associated with the individual's history of prenatal alcohol exposure and plan strategies and interventions that can most effectively support both the individual and their family.

Adjusting Expectations

Caregivers should adjust their expectations of the person with an FASD to the developmental stage they are at in that moment. Expect variability: some days they may seem to function well, and other days they will have frequent struggles. This is typical but not intentional. Provide additional support when they become overwhelmed. Learn to read their behaviors and intervene as early as possible. Know that it's okay to ask for help or support.

Strategies

Each person on the FASD spectrum is unique, and a strategy that works well with one child on the spectrum might not work at all for another. You might have to try different strategies before finding which ones work well for your family.

- Be proactive versus reactive. This will help you avoid issues before they have a chance to occur.
- Allow plenty of processing time when talking with your child. For example, when asking them a question, count 10 seconds in your head before expecting a response from them.
- Repeat instructions/tasks as many times as it takes for your child to understand what to do. It can be helpful to write down instructions and give reminders.
- Provide supervision whenever possible.
- Allow frequent breaks from activities.
- Give concrete examples and instructions; children on the spectrum can have difficulty with idioms, sarcasm, and other language that isn't straightforward.
- Set consequences that are immediate and related to what occurred.
- If your child is feeling frustrated, anxious, or irritable, provide them with a quiet space (when possible) that doesn't have a lot of sensory stimulation.

Sources:

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2. Rodríguez JJ., Smith VC. Prenatal Opioid and Alcohol Exposure: Understanding Neonatal Abstinence Syndrome and Fetal Alcohol Spectrum Disorders to Safeguard Maternal and Child Outcomes. Zero to Three. 2018;38(5):23-28.
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FASD in Adulthood

PR%F Alliance

About FASD

Prenatal alcohol exposure (or drinking alcohol during pregnancy) can cause fetal alcohol spectrum disorders (FASD). FASD refers to a range of birth defects including brain injury and physical, behavioral, and intellectual disabilities.[1] These conditions are lifelong and irreversible. Because FASD impacts people for their entire lives, it is important that information, resources, and support are available to adults who have an FASD.

Getting an FASD Assessment

The only way to determine if you have a fetal alcohol spectrum disorder (FASD) is to receive an FASD assessment. Only trained professionals can make an FASD diagnosis. FASD is often misdiagnosed because many of the characteristics look the same as mental health disorders.[2] It can also be harder to get diagnosed on the fetal alcohol spectrum as an adult, because the characteristics associated with FASD can present differently; for example, the physical features related to FASD may change and growth may normalize, complicating a diagnosis.[3]

Signs that may indicate the need for an FASD assessment include:

- History of prenatal alcohol exposure[4]
- Received many diagnoses such as ADHD, autism, reactive attachment disorder, bipolar disorder, depression, anxiety, etc.[5,6]
- Easily distracted, hyperactive, inattentive, impulsive[7]
- Consistently displays extreme behavior (aggression, emotional instability)[8]
- Been involved with the criminal justice system[9]
- Has trouble remembering things[10]
- Makes the same mistakes repeatedly[11]
- Displays difficulties in holding a job[12]
- Raised in foster care or adopted[2]
- History of chemical dependency[13]

FASD Clinics

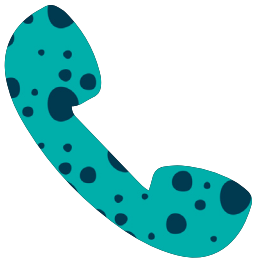
If you think you might have an FASD and want to learn more about the FASD assessment process, there are clinics across the country that can help. In Minnesota, some of the clinics that provide FASD assessments for adults are:

Canvas Health
7066 Stillwater Blvd. N.,
Oakdale, MN 55128
(651) 251-5059
www.canvashealth.org

Bluestem
124 Elton Hills Ln. NW,
Rochester, MN 55901
(507) 282-1009
www.bluestemcenter.com

Treehouse Psychology
333 Main St. N., Suite 205,
Stillwater, MN 55082
(651) 200-3788
www.treehousepsychology.com

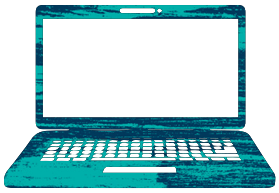
Services for Adults with an FASD



There are supports and services that can help adults with FASD lead productive, successful, and happy lives. At Proof Alliance our staff can provide one-on-one support to help you navigate services. Call our office at 651-917-2370 for more information. Some of the things we can help you with include:

- Employment services
- Housing
- Waivers and other sources of financial support
- Support groups
- Social connections

Online Help



There are a variety of online resources that are available.

- FASD Service Handbook: **http://bit.ly/FASDservicehandbook**
- Resource Directory: **http://bit.ly/ProofRD**
- Disability Benefits 101: **https://mn.db101.org**

Questions?

If you want more information, please contact Proof Alliance at 651-917-2370 or visit our website at www.proofalliance.org.

Sources:
1. Noor S, Milligan ED. Lifelong Impacts of Moderate Prenatal Alcohol Exposure on Neuroimmune Function. Frontiers in Immunology. 2018.
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Parenting Children with FASD

PR%F Alliance

Parenting a child with a fetal alcohol spectrum disorder (FASD) is a journey. It can be challenging and rewarding all at the same time. You cannot parent a child with an FASD without having it change your life. You more than likely will meet some amazing people, make lifelong friendships, and see a child work really hard to be the best person they can be with your love and support. The information below can help guide you on this unique parenting journey.

On FASD

- There is a wide range of lifelong behavioral and intellectual effects caused by prenatal alcohol exposure.[1-2] The effects of FASD can get more complex with age.[3] It is hard to see your child struggle, and you may go through periods of grief, frustration, or confusion. This may hit you at times when you are least expecting it. This is normal and there is support available.
- Learn as much as you can about FASD. Read books, attend trainings and conferences, and connect with community resources and support groups; not just at the beginning of the journey, but throughout.
- Get accustomed to educating others on FASD, including friends, family members and professionals. It is often a misunderstood disorder and is commonly known as the invisible disability.[4] FASD is a public health issue; everyone needs to know that drinking alcohol during pregnancy can cause birth defects.[5]
- Be aware that there are a number of characteristics your child might display as they grow. The different characteristics can present at different times of development, but in general you might see these effects of prenatal alcohol exposure during these particular stages:

Infants[6-12]	Toddlers[13-16]	School-Age[17-21]	Teenagers[22-25]
• low birth weight • sensitivity to light, noise, and touch • irritability • unable to suck effectively • slow to develop • ear infections • trouble sleeping	• poor memory • hyperactivity • seems to have no fear • speech and language delays	• poor social skills • easily distracted, short attention span • poor coordination • trouble with large and fine motor skills • difficulty in school	• low self-esteem • involvement with the criminal justice system • poor impulse control • must be reminded of concepts on a daily basis

Remember[26]

- FASD is a form of organic brain injury: it is permanent brain injury that causes inconsistency in behaviors and intellectual abilities on a daily basis.
- FASD is a spectrum disorder. Each person with an FASD is unique and special in their own way.
- Don't blame yourself (or the birth mother if you have adopted or are fostering a child). FASD is usually a result of misinformation, lack of knowledge, unplanned pregnancy, or alcohol use disorder. No person goes into their pregnancy willfully intending to harm their child.

Relationships[26]

- Be aware that some relationships in your life may change. Work on educating family, friends, professionals, and community members about FASD, with hope that they will be patient and understanding.
- Connect with other families raising children with an FASD. This is one of the most common desires that caregivers have, to talk with another parent who "gets it".

Patience[26]

- Be patient. Never blame the child for their brain injury. Children with an FASD may be able to repeat a rule but may not understand it or be able to apply it. This and other common cognitive symptoms of FASD can be very frustrating. Try not to get irritable or short tempered. Make respite and self-care for yourself a priority.
- Prepare to re-teach everything; even if they understand today, they may not tomorrow. Sooner or later they will likely get it.
- Know that conventional parenting techniques may not work for children with an FASD. Time-outs rarely work for kids with an FASD; the common symptom of inability to understand consequences may be the reason for this. We have to be creative and find alternative strategies like being proactive versus reactive and providing consistent supervision. Know that when we find one strategy that works, it might not work forever.

Routine & Structure[26]

- Structure and routine can give children with an FASD a sense of calm. Keeping a daily routine and letting the child know ahead of time what the plan is for each day can be an effective strategy to regulate behavior.
- Consider using visual reinforcement of daily activities through written daily schedules or calendars. Try not to make the schedule too overwhelming.
- Prepare for transitions such as getting in and out of the car or bathtub, going to sleep, going to school, a change in television programs, etc. This preparation will look differently for each child; for some children a sand time or countdown timer seems to work well, for others timers may cause anxiety. Children with an FASD don't always have the ability to make transitions from one emotional state or one activity to another. Be prepared to support them find what works for them.
- When giving instructions, be concrete, specific and allow extra processing time. Children with an FASD may not be able to see the parts of a whole nor understand a sequence. Help them by breaking down tasks into smaller, more manageable steps, communicating one at a time and repeating as many times as needed.
- Learn to distinguish between flexibility and chaos. Allowing spontaneous change doesn't mean the whole schedule is done for that day. Structure can mean many things. Be understanding and supportive by being flexible or having a backup plan especially if the child is going to a new or high sensory place.

Health[26]

- A healthy nutritious diet helps with physical and mental health. Consult your primary physician to see if there is a specific diet that could be more effective for your child.
- All children need exercise for muscle and motor development. Try out different activities to see what fits best such as swimming, rock climbing, biking, basketball, etc. For some children with an FASD, team sports can be a challenge but also prevent isolation. Being a part of a team or getting involved in a club or community group can also help with self-perception.
- Many children with FASD have poor sleeping patterns. To promote healthier sleep, establish evening routines before bedtime and use a visual schedule to depict the bedtime routine. Maintain a consistent bedtime and wake-up time throughout the week. If your child has sensory issues, you might try massage, white noise, ear plugs, turning pajamas inside out, or other ways of addressing sensory challenges.

School[26, 27]

- Educate and work with your child's school to find what works best. Some examples are: one-on-one support, sensory breaks/tools, and/or reduced or no homework. This can reduce household tension in the evenings and respect the child's exhaustion level.
- Work with your child's teachers to have a flow of communication between home and school. This can create both a stronger home and school environment for the child.
- Ask your child's teacher to let you know if there are going to be any upcoming changes at school, such as a substitute teacher, a fire drill, or an activity that isn't usually part of the daily routine. Children with FASD thrive on consistency, and helping them prepare for a change can make the process less stressful for them.

Parenting Children with FASD

PR%F Alliance

Have Fun[26]

- Have fun every day! The symptoms of FASD can create tension and stress within families so make sure you find something positive and fun each day. It can be simple and short, but it is really important to do.
- Make sure your child knows you love them. Reinforcing attachments ensures they know that, no matter what, you are there for them. This may look different for each child; it might be lots of cuddles, actively listening to them about their day or simply stating "I love you" during stressful situations.
- Remember that your child is a kid like any other who wants love and acceptance. Accept them for who they are and meet them where they are at each day. Ask yourself, "Where are they at today?" before setting expectations.
- Learn to expect chaos and celebrate when you are wrong!

Websites

- Proof Alliance: www.proofalliance.org
  - Calendar: www.proofalliance.org/calendar/
  - FASD Service Handbook: www.proofalliance.org/support-and-resources/fasd-service-handbook/
  - Resource Directory: www.proofalliance.org/directory/
  - Books and Videos: www.proofalliance.org/support-and-resources/resources/books-and-videos/
- National Organization on Fetal Alcohol Syndrome: www.nofas.org
- Center for Disease Control and Prevention: www.cdc.gov/ncbddd/fasd/index.html

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#10858

A Report to North Dakota on Fetal Alcohol Exposure and Fetal Alcohol Spectrum Disorders

From North Dakota Fetal Alcohol Syndrome Center (2019)

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Why emphasize prenatal alcohol exposure?

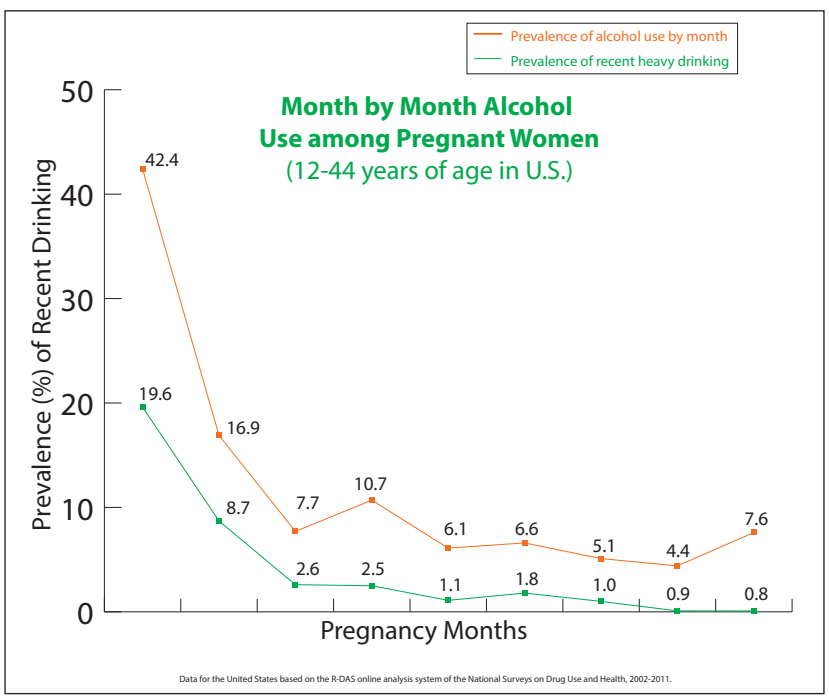
Prenatal alcohol exposure often occurs with other substance abuse and is often not detected. Of all the substances of abuse (including cocaine, heroin, and marijuana), alcohol produces by far the most serious adverse effects for the fetus.

Effect	Alcohol	Marijuana	Cocaine	Heroin	Tobacco
Low Birth Weight	■		■	■	■
Impaired Growth	■				
Facial Malformation	■				
Small Head Size	■				
Intellectual and Development Delays	■	■			
Hyperactivity, Inattention	■	■		■	■
Sleeping Problems	■	■	■	■	■
Poor Feeding	■		■		
Excessive Crying	■	■	■	■	
Higher Risk for Sudden Infant Death Syndrome	■			■	■
Organ Damage, Birth Defects	■				
Respiratory Problems	■			■	■

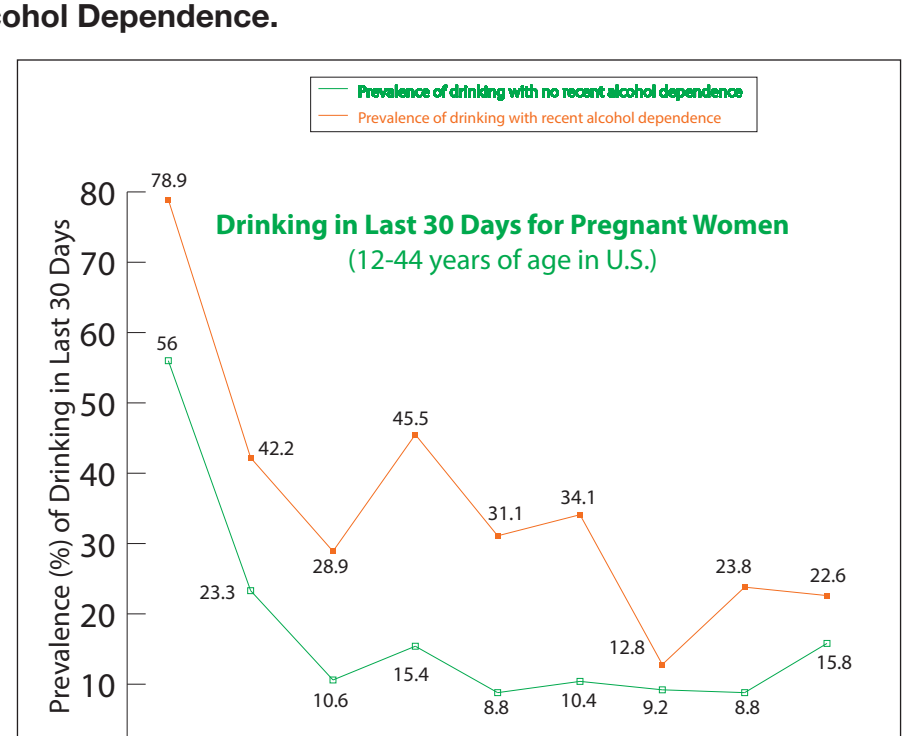
http://www.faslink.org/DrugEffectOnPrenatalDevelopment.html

Prevalence of Prenatal Alcohol Exposure

Two recent studies demonstrate the magnitude of prenatal alcohol exposure in the United States. This data is similar to rates obtained from four sites in North Dakota over the past 30 years.



Prenatal Alcohol Exposure is Increased in Women With Current or a History of Alcohol Dependence.



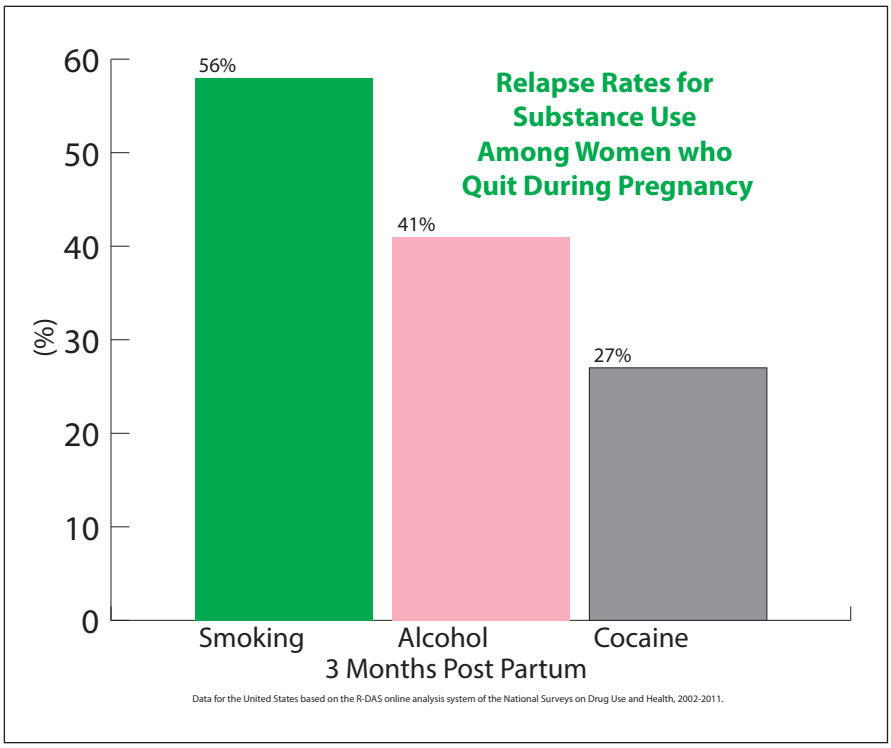
This data demonstrates the need for a systematic approach to screening for prenatal alcohol exposure during prenatal care, after delivery, and during well child care.

North Dakota had
3,400 women using alcohol
during pregnancy in 2017

Heavy users who drink
all 40 weeks of pregnancy = 162

After birth, relapse is common.

Many women who quit drinking, smoking, or using drugs during pregnancy begin again right after the birth of the baby. The importance of screening during well child care is demonstrated by the following data. Early detection provides an opportunity to prevent exposure in a subsequent pregnancy by use of office based interventions.



Drinking while breastfeeding.

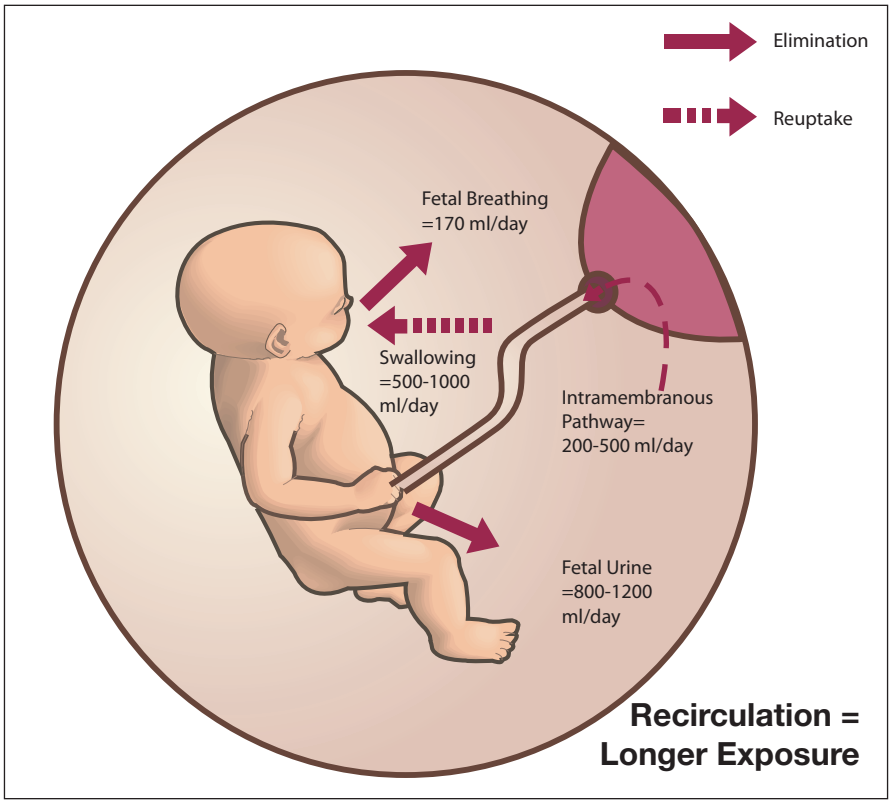
Among women who drank and breastfed (71%), alcohol use was associated with increased rates of neurobehavioral impairments and growth deficits. Drinking while breastfeeding is not recommended (May et al., 2016).

Prenatal substance exposure increases the risk for adverse outcomes for the fetus by three fold.

(Lamy et al., 2016).

Mechanisms of Exposure Differ by Gestational Age.

Pathways of ethanol entry and removal from the fetal compartment and amniotic fluid change as pregnancy progresses.

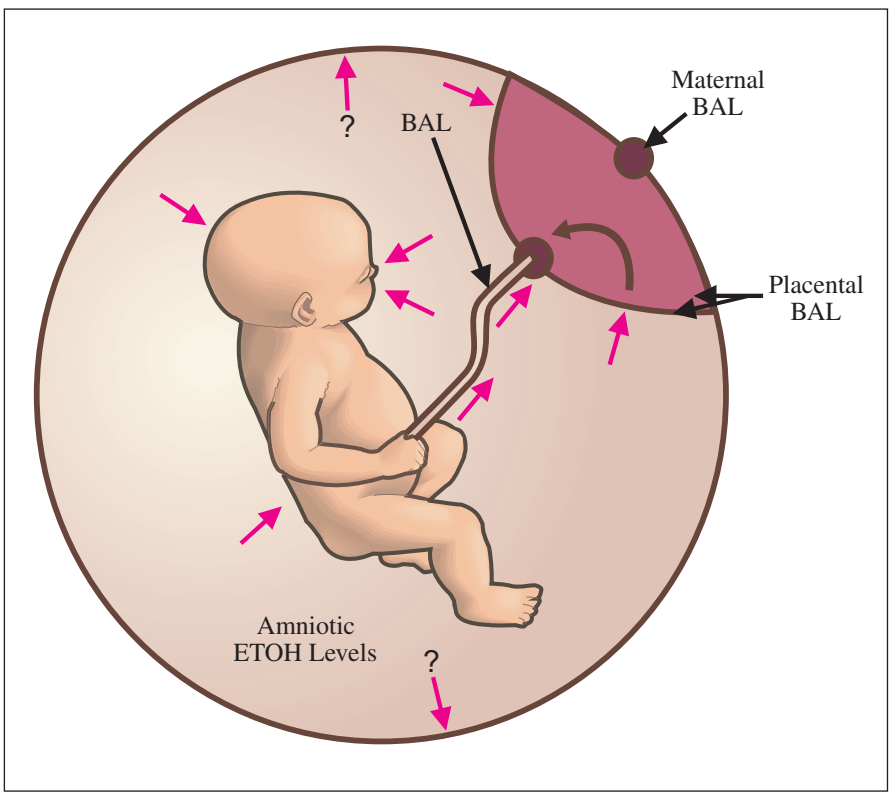


Importantly, exposure is multigenerational.

When a pregnant woman drinks she exposes herself, the fetus and the fetal germline.

The physiology of fetal alcohol exposure changes across gestation.

Early in pregnancy placental, fetal, and amniotic fluid concentrations of alcohol exposure are equivalent. Beginning in mid-pregnancy, the maturing fetal epidermis adds keratins which decrease permeability resulting in development of a barrier between fetal circulation and the amniotic fluid. By 30 gestational weeks, development of barrier function alters the pathophysiology of ethanol dispersion between the fetus and amniotic fluid. Firstly, increases in the effectiveness of barrier function decreases the rate of diffusion of alcohol from fetal circulation across fetal skin into the amniotic fluid. This reduces the volume of alcohol entering the amniotic fluid. Secondly, fetal barrier function increases the duration of fetal exposure by decreasing the rate of alcohol diffusion from amniotic fluid back into fetal circulation (Longhurst et al., 2016). Ethanol is then transported into maternal circulation for metabolism or elimination. This increases the duration of exposure from each episode of drinking.



Fetal Exposure

FASD: What about the men?

Prenatal Alcohol Exposure

Increased risk of impotence 8%[1]

Lack of sexual desire increased 31% to 58%[2]

Double the risk of erectile dysfunction[3]

Decreased sperm (volume, motility, and abnormal sperm)[4,5]

Increase in risk of miscarriage 2-15 times[6]

Women drink with partner over 75% of the time[7]

Drinking is initiated by man over 40% of the time[7]

Increased risk of fetal death[6, 8]

Decreased birth weight[9]

Late start to prenatal care[10]

Fewer prenatal visits[10]

1. Lemere et al 1973 Am J Psychiat 130: 212-213; 2. Whalley et al 1978: Acta Psychiat Scand 58: 281-298; 3. Jensen SB 1984: Acta Psychiat Scand 69: 543-549; 4. Gumus et al 1998: Int Urol Nephrol: 30 755-759; 5. Muthusami et al 2005: Fertility adn Sterility 84: 918-924; 6. Henriksen et al 2004; Am J Epidemiol: 160 661; 7. McBride et al 2012: Global Health Promotion 19: 102-114; 8. Muthusami et al 2005: Fertility and Sterility 84: 918-924; 9. LIttle et al 1987: Teratology 36: 59-65; 10. Burd et al 2003: Neurotoxicoloty and Teratology: 25(6) 681-688.

Polysubstance Abuse Increases Risks.

In substance abuse additional risks produce multiplicative risk enhancement especially for polysubstance abuse. This demonstrates the potential effect of risk reduction by reducing the multiplicative effects from each risk marker.

Increased Risk for Fetal Alcohol Spectrum Disorders From Combined Exposures

15% Risk Interactions 15%

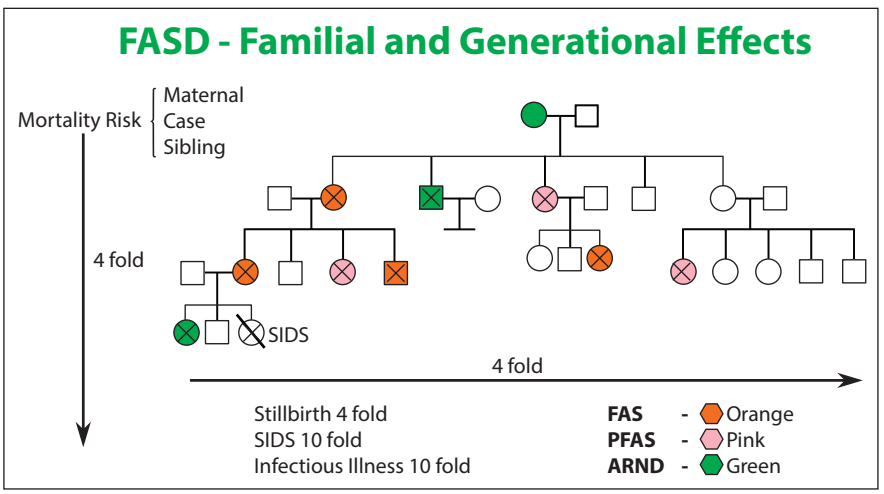
Additive = 30%

Multiplicative = 46%

Odendall et al., 2009, Gynec & Obstet Invest

Exposure is often generational and familial.

In North Dakota sequela of prenatal alcohol exposure increases over generations and within sib ships.



Detection of Prenatal Alcohol Exposure

We have well developed detection programs for prenatal alcohol exposure in North Dakota where over 90% of pregnancies have at least one systematic screen during pregnancy. We utilize the One-Question Screen.

Exposure Assessment — **How We Do It**

Exposure

When was your last drink?

Risk Stratfication

Before	Pregnancy	
	Pre-awareness	Post-awareness
Unexposed	Exposed	Exposed & High Risk

Dosimetry

Charting PAE 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)

What is a drink? Alcohol % ____ Drink vol ____

When a history of prenatal alcohol exposure is not available, we use the Maternal Risk Score for exposure risk stratification.

Estimating Exposure Risk

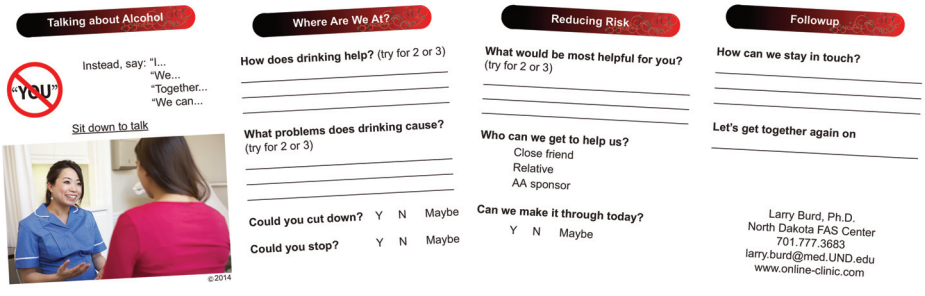
Maternal Risk Score

			Score
_____	Age over 25 years		
_____	Unmarried, divorced, widow, living with partner		
_____	On TANF, WIC, Social Security or income < $16,000 per year		
_____	Did not graduate from high school		
_____	Poor diet	Check Any One Add 5	_____
_____	Smokes more than 1/2 pack per day		
_____	Drinks, but less than 2 days/week & less than 2 drinks /drinking day	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 died		
_____	Previous child with FASD, or developmental disability		
_____	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)		
_____	Uses inhalants, sniffs or illegal drugs	Check Any One Add 45	
			_____

Score	Risk Category	Recommendations
0	None	Standard prenatal care
5	Low	Standard prenatal care
20-40	Moderate	Standard Prenatal care and FASD education
45-50	High	High risk pregnancy, alcohol-drug abuse treatment
55-105	Very High	High risk pregnancy, alcohol-drug abuse treatment

Total Score ☐

We have recently added an in-office intervention strategy for prenatal care providers in North Dakota. Training across all prenatal care sites is ongoing.



Prenatal alcohol exposure predicts increase in risk for adverse outcomes.

Ideal screening opportunities are:

Prior to pregnancy
At the first prenatal visit
During pregnancy
At delivery
During at least one well child visit

Screening for prenatal alcohol should be multi-tiered. Screeners need training to be even modestly effective.

How common is fetal alcohol spectrum disorder (FASD)?

1-5% of all live births
In North Dakota we have 11,000 births each year, So we have between 110-550 affected babies born each year. Only 5-15% will ever be diagnosed with FASD. Nearly 90% will never be treated for FASD.

A snapshot of FASD in North Dakota

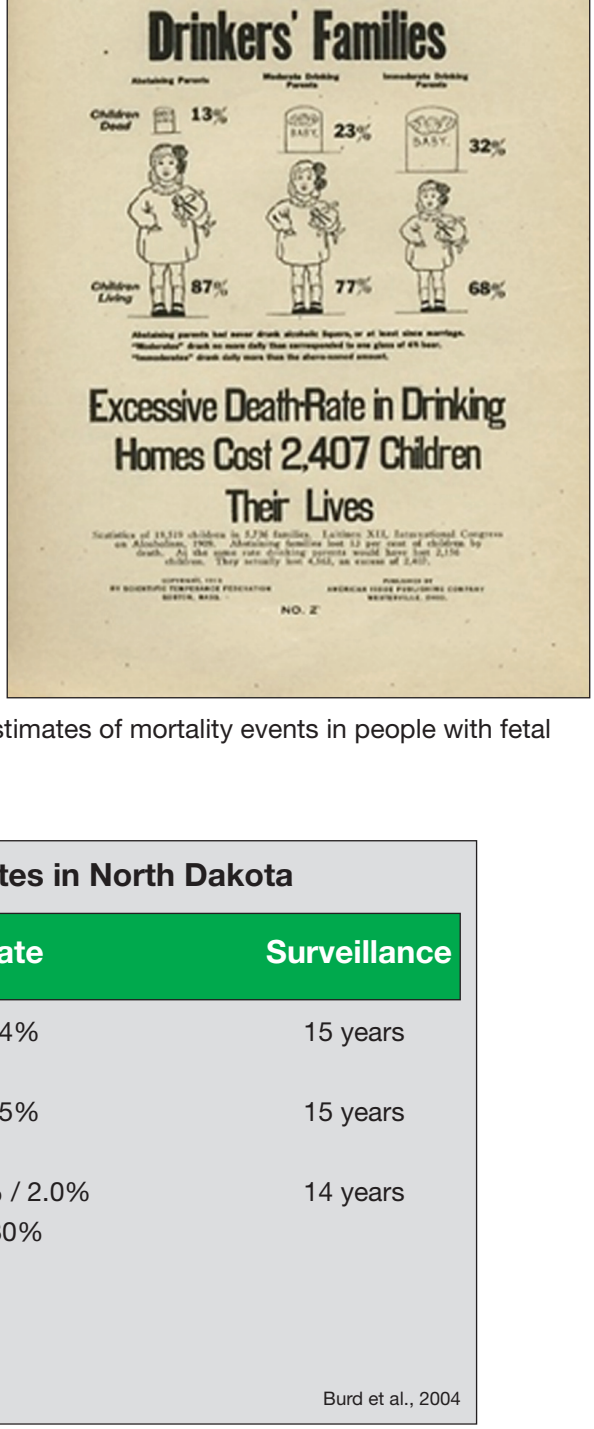
New cases born each year 110-550
Annual cost for new cases (330 cases = $7.5 million)
Birth - 18 years of age cohort (1,980-9900)

As a comparison for every case of neonatal abstinence syndrome we have 7-35 cases of FASD in North Dakota

[1] Greenmeyer et al 2018.

Prenatal alcohol exposure increases mortality risk.

Mortality in clinical settings often occurs before a diagnosis of prenatal alcohol exposure or fetal alcohol spectrum disorder is diagnosed. Thus, mortality estimates in clinical settings are often very low. Alcohol exposure has been a cause of concern for increased mortality for over 100 years.



However, in North Dakota we have excellent estimates of mortality events in people with fetal alcohol spectrum disorder.

FASD Mortality Rates in North Dakota

Population	Rate	Surveillance
FASD	5.4%	15 years
Maternal	4.5%	15 years
Sibling	11.4% / 2.0% 530%	14 years

- Infectious OR 13.7
- SIDS OR 10.2

Burd et al., 2004

Mortality Publications

Thompson, A., Hackman, D., & Burd, L. Mortality in fetal alcohol spectrum disorders. *Open Journal of Pediatrics* 2014, 4(1), 21-33.

Burd, L., Peterson, L., & Kobrinsky, N. Fetal Alcohol Spectrum Disorders and Childhood Cancer: A Concise Review of Case Reports and Future Research Considerations. *Pediatr Blood Cancer* 2013, doi: 10.1002/pbc.24886

Burd, L., Klug, M.G., Bueling, R., Martsolf, J., Olson, M., & Kerbeshian, J. Mortality Rates in Subjects with Fetal Alcohol Spectrum Disorders and Their Siblings. *Birth Defects Research (Part A)* 2008, 82(4), 217-223.

Eaglestaff, M.L., Klug, M.G., & Burd, L. Eight Years of Infant Mortality Reviews in the Aberdeen Area of the Indian Health Service. *The IHS Provider* June 2007, 174-180.

Eaglestaff, M.L., Klug, M.G., & Burd, L. Infant Mortality Reviews in the AAIHS: Strategies and Outcomes. *Public Health Reports* 2006, 121(2), 140-148.

Burd, L., Klug, M.G., & Martsolf, J.T. Increased Sibling Mortality in Children with Fetal Alcohol Syndrome. *Addiction Biology* 2004, 9, 179-186.

Burd, L., & Wilson, H. Fetal, Infant, and Child Mortality in a Context of Alcohol Use. *American Journal of Medical Genetics Part C* (Semin. Med. Genet.) 2004, 127C, 51-58.

Maternal mortality is hugely increased in mothers of children who have been diagnosed with a fetal alcohol spectrum disorder.

Fetal alcohol spectrum disorders (FASD) are associated with an increase in risk for mortality for people with an FASD and their siblings. In this study we examine mortality rates of birth mothers of children with FASD, using a retrospective case control methodology. We utilized the North Dakota FASD Registry to locate birth certificates for children with FASD which we used to identify birth mothers. We then searched for mothers' death certificates. We then compared the mortality rates of the birth mothers with an age matched control group comprised of all North Dakota women who were born and died in the same year as the birth mother. The birth mothers of children with FASD had a mortality rate of 15/304 = 4.93%; (95% CI 2.44-7.43%). The mortality rate for control mothers born in same years as the FASD mothers was 126/114,714 = 0.11% (95% CI 0.09-0.13%). Mothers of children with an FASD had a 44.82 fold increase in mortality risk and 87% of the deaths occurred in women under the age of 50. Three causes of death (cancer, injuries, and alcohol related disease) accounted for 67% of the deaths in the mothers of children with FASD. A diagnosis of FASD is an important risk marker for premature death in the mothers of children diagnosed with an FASD. These women should be encouraged to enter substance abuse treatment (Li et al., 2012).

Summary of the North Dakota FASD Family

THE DADS

Age	30.8
Education	10.9
Unmarried	63%
Alcoholic	12+years
Heavy Drinker	+
Treatment	<3
Low SES	+

THE MOMS

Age	27.4
Education	10.6
Unmarried	63%
Smoker	82%
Alcoholic	10+years
Treatment	>3 (45%)
Low SES	+
Poor Diet	+
Parity	3
Prenatal Visits	<5 (56%)
1st Prenatal	>1st tri (56%)
Mortality	4.9%

Previous Terminations	↑
Number of Prenatal Visits	↓
Number of Prenatal Complications	↑
Birth Weight	↓

THE CHILDREN

Age Diagnosis	7.1 Years
Older Sibs	2
Younger	2
Mean Birth Weight	-701 grams
Birth Defects	15%
Cerebral Palsy	6%
Intellectual Disability	20%
ADHD	75%
Out of Home	85%
Head Injury	15%
If FASD Diagnosis	1 dead sibling (9%)
	2 dead siblings (2%)
	3 dead siblings (5%)

Mortality

FASD Mothers	=	4.9%
Controls	=	0.11%
OR	=	44.82

50% died by age 41.5

87% died by age 50

- Cancer
- Alcohol Related — 67%
- Accidents

31.3 YPLL per case

Mortality Rate

FASD	=	5.4%
FASD Sibling	=	11.4%
Sibling Controls	=	2.0%
RR	=	530%
Infection OR	=	13.7
SIDS OR	=	10.2

Number of Prenatal Complications	↑
Number of Prenatal Visits	↓
Late Start Prenatal Care	↑
Birth Weight	↓
Number of Malformations	↑

Burd, L., Klug, M.G., Martsolf, J.T., & Kerbeshian, J. Fetal Alcohol Syndrome: Neuropsychiatric Phenomics. *Neurotoxicology and Teratology* 2003, 25(6), 697- 705

Prevalence of fetal alcohol spectrum disorder in North Dakota

FASD in North Dakota

- 1% of live births
- 20% recurrence risk
- More severe in younger siblings
- 5% ever diagnosed
- Increasing rates of neuropsychiatric disorders

Fetal Alcohol Spectrum Disorder North Dakota, 2013

Deliveries	10,591
FASD (1%)	105
Children birth-18	1,890
FASD recurrent (20%)	21
North Dakota Diagnosed	795

FASD is more prevalent than Down Syndrome, muscular dystrophy, or autism spectrum disorder.

What does FASD cost?

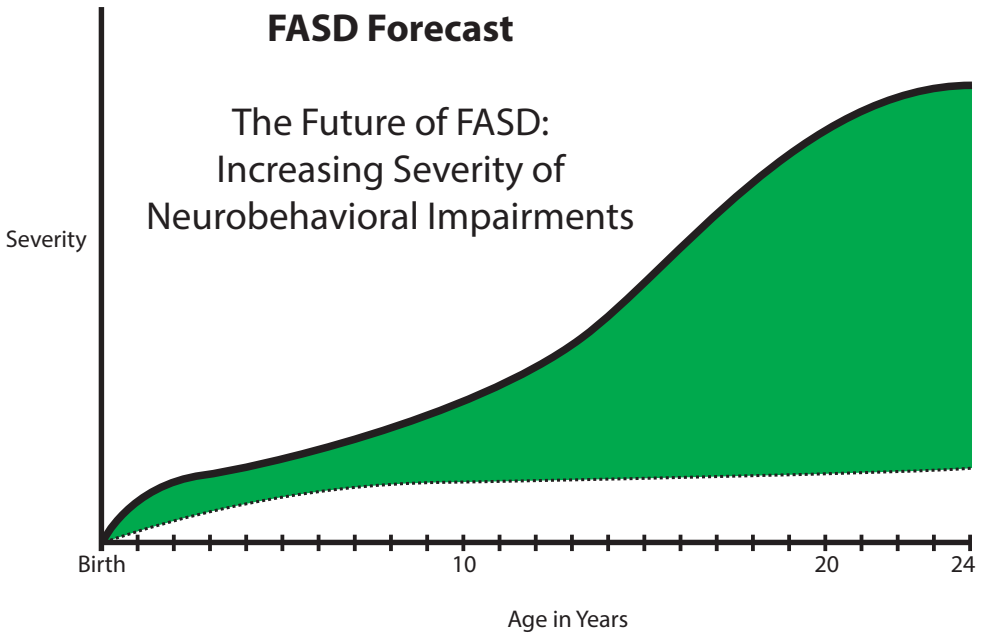
On average we hit the million dollar cost of care for FASD at age 43 years.[1]

The annual cost for FASD worldwide is $22,810/year for children. Thus each year we spend an extra $22,810/child with FASD. By 21 years of age we have spent $479,010. For adults the annual cost is $24,308, so by age 40 we will have spent another $461,852.

[1] Greenmyer, J.R., Klug, M.G., Kambeitz, C., Popova, S., Burd, L. A multicountry updated assessment of the economic impact of fetal alcohol spectrum disorder: Costs for children and adults, J Addict Med, 12(6), November/December, 2018.

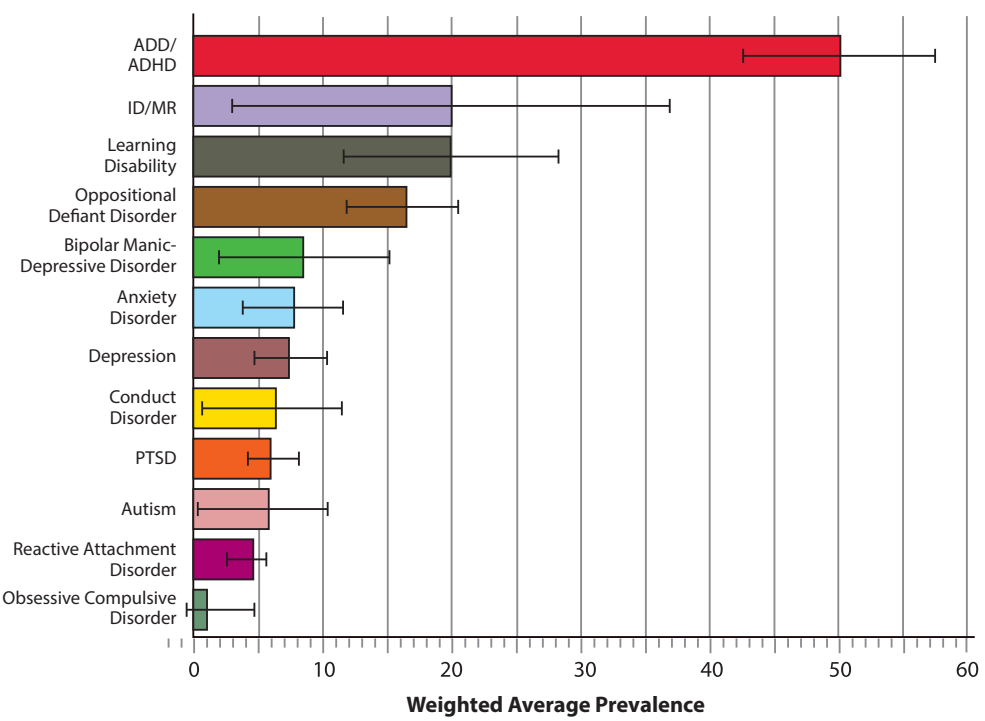
FASD becomes more complex over time.

(Burd, L. Fetal alcohol spectrum disorder: Complexity from comorbidity. Lancet, vol 387, March 5, 2016)



FASD is a huge risk enhancer for developmental disorders and mental illness

Figure 1. Percentage of Disorders Comorbid With FASD (1981-2015) (n=5,618)



Incarceration Risk for FASD

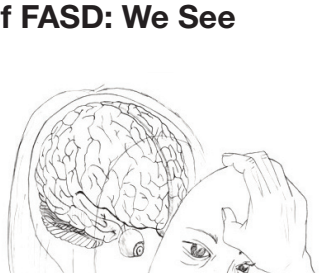
- In Canada youth 12-18 years of age with FASD have a 19 fold increase risk of incarceration.

  Popova L., Am J Epidemiol, 2012

Nearly all FASD is Alcohol Related Neurodevelopmental Disorder and not Fetal Alcohol Syndrome.

Behind the Face of FASD: We See

- ADHD
- Depression
- Cognitive Impairment
- Intellectual Disability
- Learning Disabilities
- Substance Abuse
- Judgment Deficits



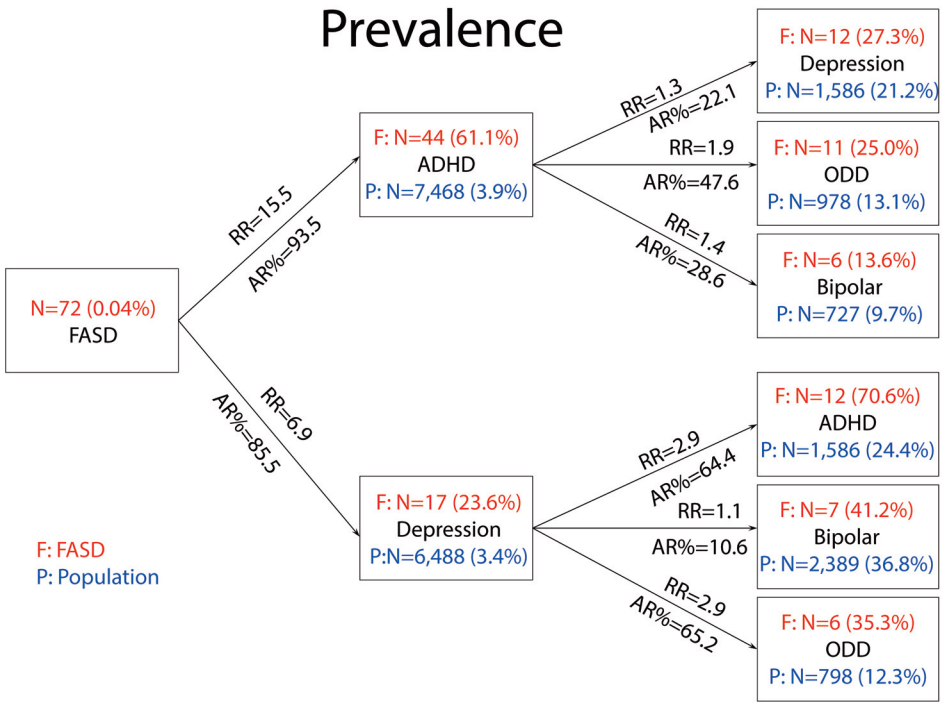
Most children with FASD are in out-of-home foster care system.

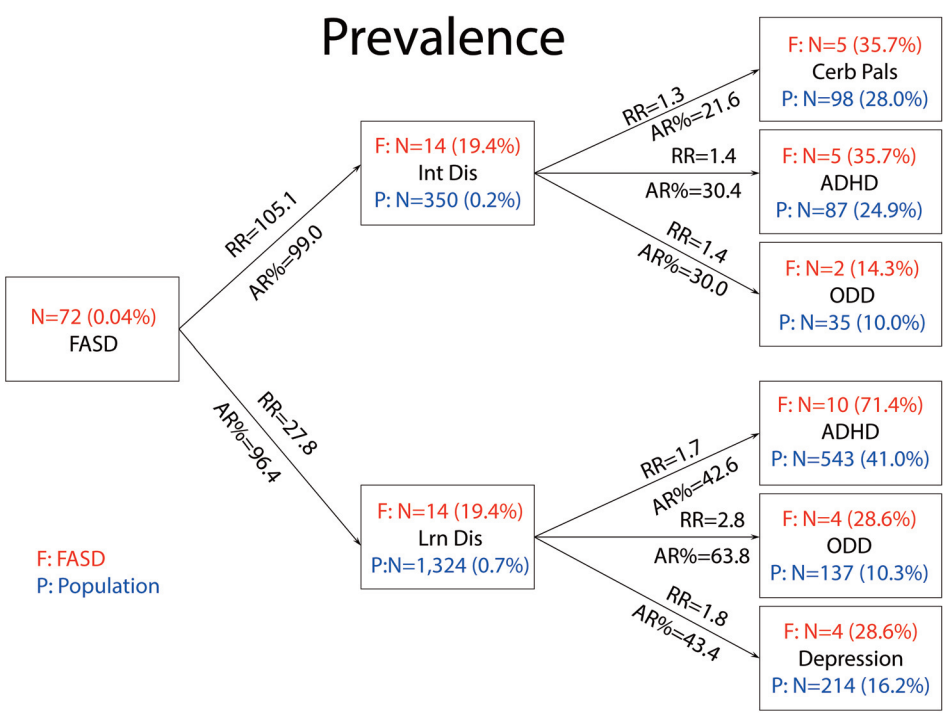
Foster Care Placement in Children (Birth - 18 Years of Age)

- FAS: 336
- ARND: 1344
- Total FASD: 1680
- Years of Foster Care: 768

Several hundred hours of foster care are required every year for children with FASD in North Dakota.

FASD is a large and enduring risk enhancer for development of mental disorders and developmental disabilities.





The costs for health care, mental health are greatly increased for children with FASD.

Fetal alcohol syndrome (FASD) is a common developmental disability. FASD is thought to be 100% preventable. While this is a theoretical truth, a prevention rate of 100% appears unlikely in the near future. However, several prevention strategies are available. In this paper, we examine the potential cost savings from prevention of one case of FASD each year in the state of North Dakota. We utilized the North Dakota Health Claims Database to examine annual cost of health care for children birth through 21 years of age with FASD and controls. The mean annual cost of health care for children birth through 21 years of age with FASD was $2842 (n = 45). This is $2342 per capita more than the annual average cost of care for children in North Dakota who do not have FASD ($500 per year).

Prevention of one case of FASD per year in North Dakota would result in a cost savings of $128,810 in 10 years and $491,820 after 20 years. After 10 years of prevention, the annual savings in health care costs alone for one case of FASD would be $23,420 (Klug & Burd, 2003).

Popova et al have completed a series of cost of care estimates for FASD in Canada that are likely to be useful in North Dakota.

Popova, S., Lange, S., Burd, L., & Rehm, J. Health care burden and cost associated with fetal alcohol syndome: Based on official Canadian data. PloS ONE, 2012, Aug. 7(8) e43024 doi:10.1371/journal.pone.0043024.t004.

Popova, S., Lange, S., Burd, L., Urbanoski, K., & Rehm, J. Cost of specialized addiction treatment of clients with fetal alcohol spectrum disorder in Canada. BMC Public Health 2013, 13(6) 570. http://www.biomedcentral.com/1471-2458/13/570

Popova, S., Lange, S., Burd, L., Shield, K., & Rehm, J. Cost of speech-language interventions for children and youth with Fetal Alcohol Spectrum Disorder in Canada. *International Journal of Speech-Language Pathology* 2014, 16(6), 571-581.

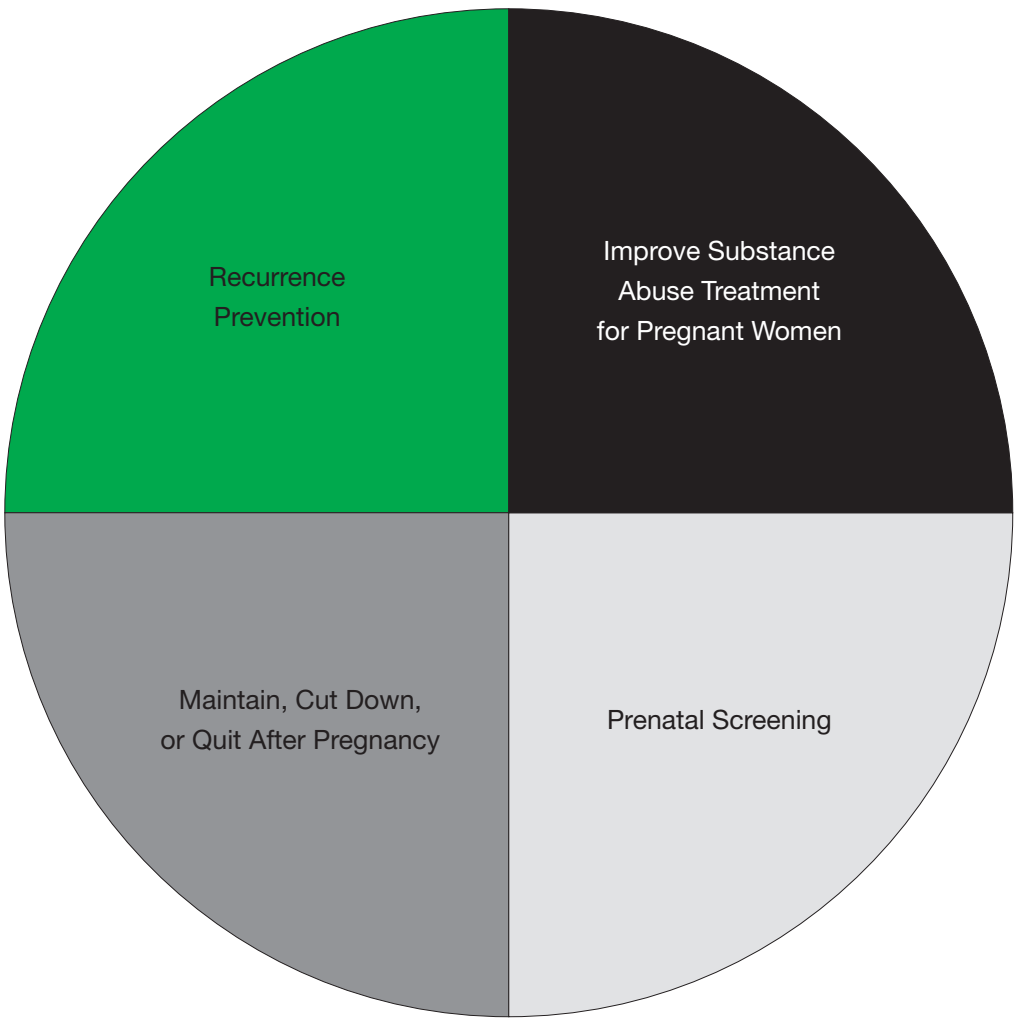
Popova, S., Lange, S., Burd, L., & Rehm, J. Canadian children and youth in care: The cost of fetal alcohol spectrum disorder. *Child Youth Care Forum* 2014, 43(1) 83-96.

Easton, B., Burd, L. Sarnocinska-Hart, A., Rehm, J, & Popova, S. Productivity losses because of morbidity attributable to fetal alcohol spectrum disorder in Canada: A demographic approach. *Journal of Studies on Alcohol and Drugs* 2014 Nov. 75(6), 1011 1017.

Popova, S., Lange, S., Burd, L., Rehm, J., Cost attributable to Fetal Alcohol Spectrum Disorder in the Canadian correctional system. *International Journal of Law and Psychiatry* 2015, 41, 76-81.

Popova, S., Lange, S., Burd, L., Nam, S., & Rehm, J. (2016). Special education of children with Fetal Alcohol Spectrum Disorder. *The Exceptionality*. Published online March 23. From http://dx.doi.org/10.1080/09362835.2015.1064415.

Prevention strategies for prenatal alcohol exposure and FASD in North Dakota. (Always Reduce Smoking).



Prevention of fetal alcohol spectrum disorder is one of the most effective strategies for reducing the cost of health care, foster care, special education, juvenile justice, developmental disabilities, substance abuse treatment, and in the corrections system.

This table models cost of prevention by risk level using alcohol treatment as the intervention when treatment 50% effective.

Alcohol Use & Other Risk Factors	Risk of FASD	Women Treated	Women Quit[a]	Cases Prevented	Cost Per Case Prevented
Daily alcohol use	0.01%	20,100	10,000	1	$100,000,000
Heavy Drinkers, middle class, non-smokers	.29%	690	344	1	3,450,000
Heavy drinkers, low income, smokers, poor diet	4.3%	47	23	1	235,000
Women who have had a previous child with FASD	75.0%	3	1	1	15,000

Additional information and more detailed modeling data are available at: http://www.online-clinic.com on FASD Exposure Model.

[a]Quit after 1 year.

2021 SENATE STANDING COMMITTEE MINUTES

Human Services Committee
Sakakawea Room, State Capitol

HCR 3011
3/30/2021

A concurrent resolution directing the Legislative Management to consider studying fetal alcohol spectrum disorders (FASDs), including treatment, services available, potential prevention, and whether existing policies for children and adults are appropriate.

Madam Chair Lee opened the discussion on HCR 3011 at 4:16 p.m. Members present: Lee, K. Roers, Hogan. Anderson, Clemens, O. Larsen.

Discussion Topics:

- Study intent
- Alcohol quantity and frequency
- Fetal alcohol gene

Senator O. Larsen moves **DO PASS.**
Senator Anderson seconded.

Senators	Vote
Senator Judy Lee	Y
Senator Kristin Roers	Y
Senator Howard C. Anderson, Jr.	Y
Senator David A. Clemens	Y
Senator Kathy Hogan	Y
Senator Oley Larsen	N

The motion passed 5-1-0
Senator Anderson will carry HCR 3011.

Additional written testimony: N/A

Madam Chair Lee closed the discussion on HCR 3011 at 4:31 p.m.

Justin Velez, Committee Clerk

2021 SENATE STANDING COMMITTEE MINUTES

Human Services Committee
Sakakawea Room, State Capitol

HCR 3011
3/31/2021

A concurrent resolution directing the Legislative Management to consider studying fetal alcohol spectrum disorders (FASDs), including treatment, services available, potential prevention, and whether existing policies for children and adults are appropriate.

Madam Chair Lee opened the discussion on HB 3011 at 10:22 a.m. Members present: Lee, K. Roers, Hogan, Anderson, Clemens, O. Larsen.

Discussion Topics:

- Implementation of recommendations
- Funding
- Public awareness
- Austism

[10:23] Pamela Sagness, Director, Behavioral Health Division, DHS. Provided the committee with ND Task Force on Substance Exposed Newborns Report to Legislative Management (testimony #11173) and the Substance Exposed Newborns Summary of Recommendations (testimony #11174 and #11175).

Senator K. Roers moves to **RECONSIDER COMMITTEE ACTION ON DO PASS.**
Senator Hogan seconded.

Senators	Vote
Senator Judy Lee	Y
Senator Kristin Roers	Y
Senator Howard C. Anderson, Jr.	Y
Senator David A. Clemens	Y
Senator Kathy Hogan	Y
Senator Oley Larsen	Y

The motion passed 6-0-0

Additional written testimony: (1)

Carl Young, Family Services Network, INC. Written testimony #11231 of Overlapping Characteristics & Related Mental Health Diagnoses in Children research data.

Madam Chair Lee closed the discussion on HCR 3011 at 10:44 a.m.

Justin Velez, Committee Clerk

#11173

North Dakota Task Force on Substance Exposed Newborns (2015-2016)

Report to Legislative Management

FINAL REPORT
June 17, 2016

I. Introduction

Senate Bill 2367 in the sixty-fourth Legislative Assembly created a task force on substance exposed newborns "for the purpose of researching the impact of substance abuse and neonatal withdrawal syndrome, evaluating effective strategies for treatment and prevention and providing policy recommendations." The task force was directed to provide a report on its findings and recommendations to legislative management before July 1, 2016. The members of the task force hereby submit this report in fulfillment of their obligation under the senate bill.

The task force on substance exposed newborns was comprised of representatives of state agencies, the legislature, medical providers, nonprofit entities focused on children's health and wellbeing, Indian tribes, law enforcement, and the foster care community.[1] The membership represented diverse viewpoints and experiences. This diversity was essential to developing a fuller understanding of the myriad of issues involved with substance exposed newborns. The task force noted, however, that one key group of specialists was not represented. Due to the importance of prevention and early intervention, the task force believed it would have benefitted from having a member who is an obstetrician. Nonetheless, the task force brought together many stakeholders to address this important issue.

Senate Bill 2367 required the task force to meet quarterly for one year, beginning in the fall of 2015. It also set forth four goals for the task force to address during that one-year period. They were:

1. Collect and organize data concerning the nature and extent of neonatal withdrawal syndrome from substance abuse in this state;
2. Collect and organize data concerning the costs associated with treating expectant mothers and newborns suffering from withdrawal [from] substance abuse;
3. Identify available federal, state and local programs that provide services to mothers who abuse drugs or alcohol and to newborns who have neonatal withdrawal syndrome and evaluate those programs and services to determine if gaps in programs or ineffective policies exist; and
4. Evaluate methods to increase public awareness of the dangers associated with substance abuse, particularly to women, expectant mothers and newborns.

The task force has gathered data and information on these four issues and discussed them at length during its meetings. The task force recognizes the budget limitations state government faces and developed its recommendations based on best practices with the budget reality in mind.

[1] S.B. 2367 dictated how the members of the task force were selected and is attached as Exhibit A. A full list of the members is attached to this report as Exhibit B.

II. Data concerning the nature, extent and cost of neonatal withdrawal syndrome in North Dakota

Neonatal withdrawal syndrome (also known as neonatal abstinence syndrome or NAS) is the severe group of symptoms experienced by newborns whose mothers used alcohol or other addictive drugs during pregnancy. When a pregnant mother uses these substances, the substances pass through the placenta to the baby, and the baby becomes addicted to them. When the baby is born, the supply of the alcohol or drugs ends, and the baby suffers withdrawal. The acute symptoms of NAS in a newborn baby include: excessive or high-pitched crying, vomiting, diarrhea, feeding difficulty, low birth weight, fevers, seizures, respiratory distress, sensitivity to light and noise, irritability, sleep difficulty, sweating, tremors and more. The chronic symptoms may include lifelong physical and developmental impairments requiring specialized services from health care providers, social services and educators. The exact symptoms a child experiences depend on multiple factors, including the drug at issue, its dose and frequency, the child's and mother's metabolic and excretory rates and the timing of the last intrauterine exposure to the drug.

The task force identified a lack of data regarding the incidence of NAS in North Dakota. Although several states have examined this issue, it remains difficult to quantify and qualify. Many children who were exposed to alcohol or drugs in utero are simply not identified prenatally or at birth.[2] This stems, in part, from the fact that hospitals generally do not screen all newborns for NAS. Different hospitals in the state have different policies on when and how to screen for NAS. Additionally, medical records and insurance records may not specify that a child has NAS, so reviews of these records are an unreliable method for determining the incidence of NAS. For example, medical records may identify only certain symptoms of the syndrome rather than the syndrome itself.[3] Further complicating the collection of data is the fact that the signs and symptoms of NAS may not manifest until after discharge from the hospital. Some symptoms of NAS resulting from opioids may be delayed until five or more days after birth, for example.[4] For these and other reasons, the incidence data presented in this report is, at best, an estimate that almost certainly errs on the side of underreporting.

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[2] U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, "Substance-Exposed Infants: State Reponses to the Program, p. 18 (2009).

[3] Hospitals and insurers use codes from the International Statistical Classification of Diseases and Related Health Problems (ICD) to identify patients' diagnoses. The ICD is on its 10th revision, and the codes are now known as ICD-10 codes. The ICD-10 code for "neonatal withdrawal symptoms from maternal use of drugs of addiction" is P96.1. Providers may use a myriad of other codes for a newborn with NAS, however. For example, the records for a child with NAS may include Code P22.8 "other respiratory distress of newborn," Code P92.9 "feeding problem of newborn (unspecified)," or any of the several codes for low birth weight or other symptoms of NAS.

[4] Committee on Drugs and Committee on the Fetus and Newborn, *Neonatal Drug Withdrawal*, Pediatrics (Feb. 2012) http://pediatrics.aappublications.org/content/129/2/e540#T2.

A. *National Data on Incidence and Cost of NAS:*

According to the National Institutes of Health (NIH), 21,732 babies were born with neonatal abstinence syndrome (NAS) in the United States in 2012.[5] Not only is this a large number in itself, especially considering it most likely underreports the issue, it also represents a 500 percent increase since 2000.[6] NIH found that babies with NAS are more likely to have respiratory problems and low birth weights, contributing to an average neonatal hospital stay of 16.9 days for them.[7] As a comparison, babies without NAS have an average neonatal stay of only 2.1 days.[8] Similarly, other researchers found the number of neonatal intensive care unit stays due to NAS increased 700 percent between 2004 and 2013 and the average length of those stays increased from 13 days to 19 days during that time period.[9] Researchers and public health agencies agree the incidence of NAS is growing significantly.

Many researchers and commenters have attributed the increase in NAS, at least in part, to the rapid growth in the national opioid abuse epidemic.[10] The epidemic includes abuse of both prescribed and illegal opioids such as heroin. Opioids are not the only drugs that cause NAS, however. Cocaine, barbituates, alcohol and methamphetamines are some of the many other contributors to NAS.

According to the NIH, the lengthy neonatal hospital stays for babies with NAS in 2012 alone cost approximately $1.5 billion, with more than 80 percent of those costs (more than $1.2 billion) borne by Medicaid, which is funded jointly by federal and state governments.[11] Similarly, the National Association of State and Territorial Health Officials estimates that Medicaid covers 78 percent of babies born with NAS.[12] Beyond the neonatal period, Medicaid incurs extra health care costs for each baby born with NAS throughout his or her childhood. Tennessee's Medicaid program, for example, estimates it expends $40,000 just for the first year of life, on average, for each baby born with NAS.[13] This is nine times as much as the

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[5] National Institutes of Health, National Institute on Drug Abuse, *Dramatic Increases in Maternal Opioid Use and Neonatal Abstinence Syndrome*, www.drugabuse.gov/related-topics/trends-statistics/infographics/dramatic-increases-in-maternal-opioid-use-neonatal-abstinence-syndrome (Feb. 23, 2016). See also USA Today, *Born into Suffering: More Babies Arrive Dependent on Drugs* (July 8, 2015) (citing an article in the *Journal of Perinatology* by Vanderbilt University researchers).

[6] Id.

[7] Id.

[8] Id.

[9] 18.Anand KJ, Campbell-Yeo M. Consequences of prenatal opioid use for newborns. Acta Paediatr. 2015 Nov. 104 (11):1066-9.

[10] National Association of State and Territorial Health Officials, *Neonatal Abstinence Syndrome: How States Can Help Advance the Knowledge Base for Primary Prevention and Best Practices of Care*, p. 3 (2014).

[11] National Institutes of Health, National Institute on Drug Abuse, Dramatic Increases in Maternal Opioid Use and Neonatal Abstinence Syndrome, www.drugabuse.gov/related-topics/trends-statistics/infographics/dramatic-increases-in-maternal-opioid-use-neonatal-abstinence-syndrome (Feb. 23, 2016). Also, Testimony of Stephen W. Patrick, MD, MPH, MS, before the United State House of representatives Committee on Energy and Commerce Subcommittee on Health, Hearing on H.R. 1462 (June 25, 2015).

[12] National Association of State and Territorial Health Officials, Neonatal Abstinence Syndrome: How States Can Help Advance the Knowledge Base for Primary Prevention and Best Practices of Care, p. 5 (2014).

[13] National Association of State and Territorial Health Officials, Neonatal Abstinence Syndrome: How States Can Help Advance the Knowledge Base for Primary Prevention and Best Practices of Care, p. 6 (2014).

state's Medicaid program expends on a child without NAS during its first year of life.[14] This tremendous impact on state Medicaid budgets is one of the reasons NAS is such an urgent issue for states.

In addition to the extremely high costs of caring for a child with NAS during his or her infancy, states incur additional costs related to the child's additional needs for social services, educational interventions and health care. These needs generally stem from the child's in utero exposure to drugs and depend on many factors. Longitudinal studies have shown children exposed to drugs in utero can have lasting physical, neurodevelopmental, speech and behavioral problems including irritability, aggression, depression and others. Medicaid programs, state health and social services agencies and school systems often provide the bulk of services to address these problems.

[14] Id.

B. North Dakota Data on Incidence and Cost of NAS:

Despite the difficulty of obtaining data on the incidence of substance exposed newborns, the task force was able to find the following state-specific information for North Dakota.

The North Dakota Department of Human Services provided the following data from state Medicaid claims. Approximately 120 babies born in fiscal year 2013 were diagnosed with NAS. The average cost to North Dakota Medicaid for the first year of life for a baby born with NAS is approximately $19,300, compared to $8,200 for a baby born without NAS. Using the difference of the average costs, children diagnosed with NAS incurred medical expenses estimated to cost North Dakota Medicaid at least $1,332,000 in fiscal year 2013. Considering the impacts of underdiagnosing, increasing opioid addiction rates and increasing hospital costs, that figure has likely risen significantly since 2013.

Almost 6 percent of women who are admitted to treatment programs for substance abuse in North Dakota are pregnant.[15]

One insurer in North Dakota reviewed their claims data to help determine the incidence of NAS in North Dakota. They identified ten babies diagnosed with NAS during their neonatal period in 2014 and 2015.[16] Those babies' neonatal hospital charges amounted to more than $1,055,000. Since most babies with NAS are not diagnosed with the syndrome, these data most likely underreport the incidence and cost of NAS to insurers in our state.

At the December 17, 2015, Tribal and State Relations Committee meeting, tribal representatives noted the Three Affiliated Tribes, Spirit Lake Tribe and Turtle Mountain Tribe reported approximately 183 babies were born with NAS last year.

The North Dakota Department of Human Services found at least 67 pregnant substance abusers sought treatment at Human Service Centers in state fiscal year 2014. Pregnant women are prioritized by the centers, and all 67 women were offered services within 48 hours of contacting the centers.

Dr. Larry Burd, a longtime researcher of Fetal Alcohol Syndrome Disorder (FASD) at the University of North Dakota School of Medicine and Health Sciences, has found that approximately 80 children born in this state each year have FASD. He estimates that, "on the day before the child with FASD is born, North Dakota needs to deposit over $540,000 in the bank to cover the lifetime cost of care [for that one child]."

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[15] National Center on Substance Abuse and Child Welfare: Substance Exposed Infants, Presentation at 2011 National Conference.

[16] Specifically, the insurer identified ten babies whose initial newborn inpatient claims included the ICD-9 diagnosis codes 779 and 779.5.

While these data provide some insight into the incidence and cost of NAS, they are incomplete. To truly understand the incidence and cost of NAS in North Dakota, the state needs short- and long-term trend (year-over-year) data. Such data would also provide important information on whether any implemented interventions are effective. The first step to developing trend data is to establish a baseline. The task force recommends that individuals trained in statistical analysis and public health determine how best to establish the baseline and develop the trend data.

One group with the skills to help fill NAS data gaps is the North Dakota State Epidemiological Outcomes Workgroup (SEOW). That workgroup was initiated in 2006 by the Division of Mental Health and Substance Abuse Services in the North Dakota Department of Human Services to use relevant data to guide substance abuse prevention programming in North Dakota. It is funded with federal funds. The SEOW members also have expertise on using health care data to guide policy and program decisions relating to substance abuse. Such expertise is needed to fully quantify the incidence of neonatal withdrawal syndrome and effectively engage state residents in efforts to prevent it.

III. Discussion of Available Services and Programs and Task Force Recommendations

A major theme of the task force's discussions was that substance exposure in utero creates chronic problems for children rather than acute problems that are present only during the neonatal period. As a result, addressing the problem of substance exposed newborns really requires focus on multiple life stages of the mother and child. This report therefore includes analyses and recommendations for the following life stages: (1) pre-pregnancy, (2) prenatal period, (3) birth and neonatal period, and (4) childhood. This framework is used by other states and policymakers as well.[17]

In addition to the life stages, one overarching recommendation is to utilize the North Dakota Indian Affairs Commission office through established government to government committees such as: Tribal-State Court Affairs Committee, The Tribal-State Relations Committee, and the Tribal State Health and Human Services Committee. Currently, these committees all serve on-going Tribal, State, County, and Federal working relations in regards to Memorandums of Agreements/Understanding, Jurisdiction, and Sovereignty in working together towards common goals.

A. Pre-pregnancy

The task force members believe the best way to address newborn withdrawal syndrome is to prevent it. In order to prevent it, it is important to provide targeted education and outreach to women of childbearing age before they become pregnant. Moreover, there should be education efforts aimed at the general population so significant others, family members and friends can help reinforce them. The federal government and several other states have implemented public awareness campaigns on the dangers of substance use - usually alcohol use - during pregnancy, but data on their effectiveness are difficult to find.[18] There are several confounding variables that make it difficult to isolate the impact that these campaigns have. Nonetheless, at least in Minnesota, this type of campaign appears to have at least raised awareness of the harms of substance use during pregnancy.[19] The Department of Human Services' Behavioral Health Division is uniquely positioned in North Dakota to develop and implement an effective educational campaign along these lines, and the task force recommends that it do so.

In addition to education efforts, there also need to be adequate treatment options for women with addictions. The North Dakota Department of Human Services (DHS) licenses more than 50 private addiction treatment programs in the state.[20] These treatment programs provide multiple levels of residential and outpatient treatment. DHS also operates the state

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[17] National Association of State and Territorial Health Officials, Neonatal Abstinence Syndrome: How States Can Help Advance the Knowledge Base for Primary Prevention and Best Practices of Care, p. 3 (2014).
[18] U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, "Substance-Exposed Infants: State Reponses to the Program, pp. 22-25, 60 (2009).
[19] U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, "Substance-Exposed Infants: State Reponses to the Program, p. 60 (2009).
[20] North Dakota Department of Human Services, *Licensed Addiction Treatment Programs in North Dakota* http://www.nd.gov/dhs/info/pubs/docs/mhsa/nd-licensed-addiction-treatment-programs.pdf

hospital in Jamestown, which provides inpatient addiction treatment and eight Regional Human Services Centers that provide outpatient addiction treatment. The Regional Human Services Centers are located in Williston (Region 1), Minot (Region 2), Devils Lake (Region 3), Grand Forks (Region 4), Fargo (Region 5), Jamestown (Region 6), Bismarck (Region 7) and Dickinson (Region 8). Additionally, Regions 2, 3, 4, 5, 6, and 8 have outreach offices in smaller communities within their geographic areas.

Some patients face financial barriers to treatment, although there are many options available to make treatment more affordable. Medicaid generally covers addiction treatment, so Medicaid patients can obtain treatment if they find a provider who accepts Medicaid payment.[21] For non-Medicaid patients, the Regional Human Services Centers use a sliding scale based on a patient's income to determine charges for addiction treatment. Under the federal Mental Health Parity and Addiction Equity Act, private insurers must provide coverage for mental health care, including addiction treatment, to the same extent they cover physical health care. The specific requirements of the law are very detailed, however, and patients and providers in North Dakota have reported difficulty in obtaining insurance coverage for some types of addiction treatment services. With the passage of Senate Bill 2048 during the 64th Legislative Session, $375,000 will be available to fund a voucher system to pay for substance use disorder treatment services in North Dakota.

While some rural patients may lack access to local addiction treatment and some non-Medicaid patients may lack insurance coverage (e.g., because they opt out of employer plans and the Affordable Care Act health insurance exchange), funding for addiction treatment in North Dakota is generally good. However, the services provided are not necessarily best practice or effective. For example, medication assisted treatment options are limited and only available in limited areas of the state. In addition, funding for and access to recovery support services is limited. Individuals who access acute treatment services are often without adequate aftercare services or supports. In addition, whether patients know where to find treatment is another question. The task force heard lots of anecdotal evidence that patients and providers often lack knowledge about available treatment resources. The task force recommends that health care providers be informed of - and encouraged to refer to - the department's list of addiction treatment resources so they can refer patients as necessary. Additionally, to the extent there is funding available, the task force recommends that the Department of Human Services look for opportunities to bring health care providers and addiction treatment providers together to share information and strategies for integrating and coordinating treatment of patients.

[21] Medicaid coverage includes addiction treatment services; however, Medicaid cannot cover services for individuals age 21-64 in an Institution for Mental Disease, in residential settings except in limited circumstances under Medicaid expansion), and services for individuals who are incarcerated.

B. Pregnancy

During pregnancy, women in North Dakota have largely the same access to education and treatment options as they did before pregnancy. The department's Regional Human Services Centers prioritize pregnant women with a substance use disorder, so they can receive treatment quickly. As noted above, the Department of Human Services reports that pregnant substance abusers receive care within 48 hours of first contact with the service centers. The task force discussed the difficulty in identifying pregnant substance abusers and getting them to seek help, however.

To help identify pregnant substance abusers, the American Congress of Obstetricians and Gynecologists (ACOG) recommends universal substance use screening in early pregnancy.[22] The Association of State and Territorial Health Officials (ASTHO) suggests states can encourage this universal screening by ensuring Medicaid reimburses providers for early pregnancy visits that include screening and by helping establish screening during early pregnancy as the expected standard of care for pregnant women.[23] North Dakota's Medicaid program allows payment for substance abuse screening in conjunction with a diagnosis of pregnancy. Also, the task force recommends that universal substance use screening in early pregnancy be established as the standard of care in our state. Establishing a standard of care will require cooperation among state agencies and medical providers.

Substance abuse screening cannot occur in early pregnancy if the patient does not see an obstetrician until the end of her first trimester (as is typical), however. The task force believes medical office receptionists can play a critical role in identifying which newly-pregnant patients may be using drugs and scheduling early appointments for them. The task force recommends obstetrician offices train receptionists to ask questions designed to solicit information to identify possible substance abusers for this purpose.

If a pregnant women screens positive for substance use, her health care provider will need to know what services are available. Timely referrals to treatment services are critical to prevent and minimize the severity of NAS. Moreover, health care providers may need to provide care coordination to pregnant substance abusers (i.e. reminders and phone calls to ensure they attend medical and addiction treatment appointments). This is yet another reason why cooperation between obstetricians and addiction treatment providers is necessary. The task force recommends providers are educated on the standard of care, including medications or methadone where medically warranted, for pregnant women addicted to drugs or alcohol so appropriate interventions can be taken to minimize the incidence and severity of NAS.

Compelling addiction treatment is very difficult. In order to require a pregnant woman to obtain addiction treatment against her will, she would have to be involuntarily committed to a behavioral health services provider such as the State Hospital in Jamestown. The task force does not believe this approach would be productive as a general rule. Rather, it would likely lead to mistrust of health care providers and avoidance of prenatal care, both of which would have negative impacts on babies.

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[22] Association of State and Territorial Health Officials, *Neonatal Abstinence Syndrome: How States Can Help Advance the Knowledge Base for Primary Prevention and Best Practices of Care*, p. 2 (2014).
[23] Id.

A small handful of states have attempted to criminalize substance abuse during pregnancy. Based on data and experience, the task force strongly recommends against this approach. Early identification and intervention are critical elements in the prevention of NAS, and criminalization of drug abuse during pregnancy strongly discourages pregnant women from seeking addiction treatment and prenatal care. Without any prenatal care, a pregnant mother with an addiction is unlikely to abstain from drugs during pregnancy. As a result, criminalization appears to adversely affect babies born to addicted mothers without reducing the incidence of NAS.

C. *Birth and Neonatal Period*

The task force recognizes that, as a state, we need to fill data gaps and identify newborns with NAS in a timely manner to ensure they receive the help they need. As a result, the task force recommends that obstetricians, neonatal specialists, pediatricians and family care practitioners implement universal screening of newborns and children for NAS. There are multiple validated screening tools already available. One of the most commonly used is the Finnegan Neonatal Abstinence Scoring System. The task force recommends that the Department of Health work with providers to establish universal screening of neonates using a validated screening tool as a standard of care in North Dakota. Additionally, the task force recommends that payers cover the cost of administering the screening tool to newborns.

Under state law, if a physician believes, based on a medical assessment of a mother of newborn, that the mother used controlled substances for a nonmedical purpose during pregnancy, the physician must perform a toxicology test on the newborn.[24] If the test comes back positive or if other medical evidence of prenatal exposure to a controlled substance exists, the physician must report the results to the Department of Human Services (via the county social service office) as neglect. [25] Similarly, physicians, nurses, dentists, optometrists, dental hygienists, medical examiners, coroners, any other medical and mental health professionals, religious practitioners of healing arts, teachers, administrators, school counselors, addiction counselors, social workers, child care workers, foster parents, law enforcement officers, juvenile court personnel, probation officers, division of juvenile services employees, and members of the clergy who have knowledge of or reasonable cause to suspect child abuse or neglect must report that information to DHS if they obtained that information in their official capacities.[26] Moreover, any person may report child abuse or neglect if he or she has reasonable cause to suspect it exists.

After receiving the report, the social service office will assess the situation and make a decision about which services are necessary for the protection and treatment of the child. If the social service office finds that services are required for a newborn who has been reported as neglected, the office must also refer the child for an Early Intervention Services (EIS) evaluation. EIS are multi-disciplinary services intended to help at-risk children from birth to age five meet development milestones. They are authorized under the federal Individuals with Disabilities Education Act and are free to recipients. They are also voluntary. The state cannot require a parent to utilize EIS currently.

If child abuse[27] or neglect[28] occurs, as defined in state law, criminal charges may be brought against the perpetrator.[29] [30] The task force members discussed - but did not reach consensus on - creating an affirmative defense in law to charges of child abuse or neglect

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[24] N.D.C.C. 50-25.1-17(2). Toxicology testing – Requirements.

[25] N.D.C.C. 50-25.1-17(2). Toxicology testing – Requirements.

[26] N.D.C.C. 50-25.1-03. Persons required and permitted to report – To whom reported. Note that clergy members do not have to report if they obtain the information in their capacity as spiritual advisors.

[27] N.D.C.C. 14-09-22 Abuse of child - Penalty

[28] N.D.C.C. 14-09-22.1 Neglect of child - Penalty

[29] N.D.C.C. 19-03.1-22.2 Endangerment of child or vulnerable adult.

[30] N.D.C.C. 19-03.1-22.3 Ingesting a controlled substance – Venue for violation – Penalty.

stemming from drug use by a parent. The affirmative defense would be available if the parent agreed to periodic drug testing and home visits. Pros and cons of this approach were addressed, and no data on the advisability and effectiveness of this approach were identified by the task force.

Newborns with NAS often have symptoms, such as feeding difficulty, agitation or fussiness, after they are discharged from the hospital. Parents, foster parents and other caregivers often have little information about NAS or what to expect with these newborns. One member of the task force - a longtime foster parent who has cared for newborns with NAS - reported that he did not receive any information or instructions from social services or hospital personnel about the special needs of the NAS newborns. He also reported that three other foster families who cared for newborns with NAS also received no information on NAS or how to respond to abnormal behaviors. The task force recommends that DHS work with county social services, physicians, addiction professionals, nurses, parent education programs and others to develop informational resources for foster families that open their homes to infants with NAS. The resources should provide education on NAS, its symptoms, how to manage the symptoms, when to seek help and whom to contact for help. Ideally, a state or county agency could offer a voluntary training presentation on NAS for foster parents who would like additional information on the condition.[27]

While foster parents may have the patience and ability to get assistance from social services or health care providers when caring for a newborn with NAS, many addicted mothers may not. One such mother in North Dakota came forward in the media last year to share her experience of accidentally smothering her baby. Caring for a fussy, poorly feeding, sick baby stresses the already-stretched coping mechanisms of addicted mothers. The task force recommends that these mothers receive the same educational resources and voluntary training provided to foster parents before being discharged from the hospital after delivery.

Additionally, the task force recommends that the state provide funding for programs to help ensure the safety of NAS infants after they return home. Prevent Child Abuse North Dakota (PCAND) operates a program called North Dakota Maternal, Infant and Early Childhood Home Visiting (ND MIECHV), funded through a federal grant, which provides parent support and education during home visits. Home visitors spend time with parents, children and family members so they can provide information about child development, help families get connected with medical providers and other services, help reduce stressors for families and generally provide support so children and parents stay safe and healthy. Resources for the program are currently limited, but the program has been effective. One key to its success is the fact that the home visitors have spent significant time in their target communities so they have built trusting relationships and earned reputations for being helpful among families that need their help. This foundation has been critical for ensuring parents and family members engage with the home visitors and accept their advice. In addition to the ND MIECHV program, North Dakota also has additional programs offering some level of

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[27] The Tennessee Department of Children's Services created this type of training presentation, *Challenges of Foster Parents who Care for Infants with Neonatal Abstinence Syndrome*, available here: http://www.nationalperinatal.org/Resources/conference%20handouts/FriPlen%20Helton,%20Heather%20-%20Challenges%20of%20Foster%20Parents.pdf.

home visitation services. Home visiting programs offer a variety of family-focused services to pregnant mothers and families with infants and young children to help build strong children and families. The degree of services varies by agency, including eligibility criteria. A listing of available providers, public and private, can be found here: http://www.ndkids.org/home-visiting-directory.html

The task force recommends North Dakota expand on this type of program to ensure trained workers are able to prevent abuse and neglect of children born to addicted mothers.

Other nonprofits have developed different programs designed to meet the same goals as ND MIECHV. In West Virginia, for example, a nonprofit called Lily's Place offers wrap-around care and support to babies with NAS and their families. When a mother struggling with addiction or having difficulty caring for a baby with NAS feels stressed, she can bring the baby to Lily's Place, where the baby will receive care and the mom can receive counseling and information on childcare. This spring, a bipartisan bill called the Cradle Act inspired by Lily's Place and similar services was introduced in both the House of Representatives and the Senate and was supported by the American Congress of Obstetricians and Gynecologists and the March of Dimes. The Cradle Act would direct the Centers for Medicare and Medicaid Services to establish guidelines for these "residential pediatric care centers" and ensure they are eligible for Medicaid payments. The bill is currently pending in committees. Regardless of whether it is enacted at the federal level, North Dakota can pass legislation at the state level to provide funding for places like Lily's Place.

D. Childhood

The long-term effects of drug exposure in utero vary significantly but may include learning and behavior problems. It is important for health care providers, social workers and educators to be aware of the chronic symptoms of in utero exposure to drugs and be able to identify children who may be exhibiting them. Additionally, they will need to know what resources are available to assist children with those symptoms. The task force recommends that educational materials be developed for this purpose. Additionally, social workers should be able to provide resources and information on these issues to foster parents who care for children who are suffering from the long-term effects of in utero drug exposure, and the task force recommends that education information be developed for and provided to foster parents as well.

IV. Conclusion

The task force has fulfilled its requirements under Senate Bill 2367. After much research and discussion, the task force identified a considerable lack of data on the incidence of NAS and the effectiveness of measures to prevent and address it. The task force believes it is critical to establish baseline incidence data and to develop trend data to determine whether and to what extent the incidence is increasing or decreasing over time. Moreover, the task force's recommendations include several methods for identifying substance abusers at risk of becoming pregnant, pregnant substance abusers, babies with NAS and children suffering long-term effects of in utero exposure to substances. The recommendations also include several methods for ensuring appropriate services are available and provided to women, babies and children identified as needing them. This will require ongoing

educational campaigns directed to health care providers, women and the general public, as well as requiring the provision of multiple services for mothers who abuse substances and babies suffering from NAS.

PARENTS LEAD.ORG

#11174

Substance Exposed Newborns:
AN INTRODUCTION TO SOLUTIONS

Prenatal exposure to alcohol, tobacco, and illicit drugs has the potential to cause a wide spectrum of physical, emotional, and developmental problems for these infants. Nationally each year an estimated 400,000–440,000 infants (10–11% of all births) are affected by prenatal alcohol or illicit drug exposure. In 2013, 795 children were diagnosed with Fetal Alcohol Spectrum Disorder in North Dakota. FASD is more prevalent than Down Syndrome, muscular dystrophy, and is as common as autism spectrum disorder[1]. The harm caused to the child can be significant and long-lasting, especially if the exposure is not detected and the effects are not treated as soon as possible[2].

Following a multi-year review and analysis of existing policies and practices, the National Center on Substance Abuse and Child Welfare developed a five-point intervention framework to address the system surrounding substance exposed newborns. This framework serves as a comprehensive model that identifies five major time frames when intervention in the life of an infant can help reduce the potential harm of prenatal substance exposure. The framework illustrates that birth is one of many opportunities to positively affect intervention outcomes. Therefore, it is important to understand the extent of those opportunities and which interventions are most needed and most likely to be effective at each point in time.

Five Point Intervention Framework Overview

Including excerpt recommendations from the North Dakota Task Force on Substance Exposed Newborns report to ND Legislative Management[3]

1. **Pre-pregnancy:** During this time, interventions can include promoting awareness among women of child-bearing age and their family members of the effects that prenatal substance use can have on infants.

   Recommendations:
   Develop education materials and an awareness campaign to educate women of childbearing age, as well as their significant others and families, about the dangers of substance use/abuse during pregnancy.

   Health care providers should be informed of, and encouraged to refer patients of childbearing age with substance abuse concerns to addiction treatment resources.

2. **Prenatal:** During this time, health care providers have the opportunity to screen pregnant women for substance use as part of routine prenatal care and to make referrals that facilitate access to treatment and related services for the women who need these services.

   Recommendations:
   Medical providers who provide services to pregnant women should understand their responsibilities surrounding testing, referral, follow-up and reporting.

   Medical providers should develop consistent protocols for universal screening and testing of pregnant women.

   Medical offices that provide care to pregnant women should develop protocols to identify patients who might be substance users/abusers and schedule appointments for them early in their pregnancies so they can receive information on the dangers of substance use/abuse as soon as possible.

   Medical providers should provide best practice care to patients who are substance users during pregnancy (i.e. create a standard of care for pregnant mothers with an opioid use disorder be prescribed buprenorphine)

Five Point Intervention Framework Overview *(continued)*

3 **Birth:** Interventions during this time include health care providers testing newborns for prenatal substance exposure at the time of delivery.

Recommendation:
Medical providers should develop consistent protocols for universal screening and testing of newborns.

4 **Neonatal:** During this time, health care providers can conduct a developmental assessment of the newborn and ensure access to services for the newborn as well as the family.

Recommendations:
Hospitals and social service agencies should partner in the development of plans of safe care for each newborn born with prenatal exposure to substances, prior to discharge from the hospital following the birth.

Parents and caregivers (including foster parents) should receive training and educational materials on best practices for caring with a newborn born with prenatal exposure to substances prior to discharge.

5 **Throughout childhood and adolescence**: During this time, interventions include the ongoing provision of coordinated services for both child and family.

Recommendation:
County social services and direct service providers need training so they can better inform foster parents about care for children born exposed to substances. Social workers also need appropriate education materials and training presentations that they can offer to foster parents.

References
[1]Burd, PhD, 2016. A Report to the North Dakota Task Force on Substance Exposed Newborns: From North Dakota Fetal Alcohol Syndrome Center.

[2]https://www.ncsacw.samhsa.gov/files/Substance-Exposed-Infants.pdf

[3]Senate Bill 2367 in the sixty-fourth Legislative Assembly created a task force on substance exposed newborns "for the purpose of researching the impact of substance abuse and neonatal withdrawal syndrome, evaluating effective strategies for treatment and prevention and providing policy recommendations."

[4]https://www.ncsacw.samhsa.gov/files/Collaborative_Approach_508.pdf

This five-point intervention framework highlights opportunities for cross-system collaboration and policy development at each critical point in time, from pre-pregnancy throughout an infant's early years. The framework also integrates recommendations for best practices related to outreach, engagement, treatment, and support for mothers and their infants along the five-point continuum. The framework shows that no single system has the necessary resources, information, or influence needed to adequately serve this vulnerable mother–infant dyad and other involved family members who are likely to need services. All those who have a role in improving outcomes for such families need to collaborate in order to put the necessary policies and practices in place. These collaborations can set the stage for maternal recovery from substance use disorders, child safety, and the well-being of all those involved.

Without a comprehensive coordinated response that includes child welfare and healthcare, including obstetrics, pediatrics, substance abuse treatment, and mental health professionals, families are not well served. Cross-system initiatives lead to better results by facilitating better communication, clearly defining the roles of the various professionals who serve these families, and maximizing the resources of multiple stakeholders who have a vested interest in accomplishing shared goals[4].

The ND Task Force on Substance Exposed Newborns, 2016 Summary of Recommendations can be downloaded at parentslead.org/SubstanceExposedNewborns.pdf

NORTH DAKOTA TASK FORCE ON **SUBSTANCE EXPOSED NEWBORNS**

2016 Summary of Recommendations: Report to Legislative Management

The North Dakota Task Force on Substance Exposed Newborns was comprised of representatives from state agencies, the legislature, medical providers,
nonprofit entities focused on children's health and wellbeing, Indian tribes, law enforcement, and the foster care community.

GOAL ONE

Collect and organize data concerning the nature and extent of Neonatal Withdrawal Syndrome/Neonatal Abstinence Syndrome (NAS) from substance use/abuse in the state.

GOAL TWO

Collect and organize data concerning the costs associated with treating expectant mothers and newborns suffering from withdrawal from substance use/abuse.

GOAL THREE

Identify available federal, state and local programs that provide services to mothers who use/abuse drugs or alcohol and to newborns who have NAS* and evaluate those programs and services to determine if gaps in programs or ineffective policies exist.

GOAL FOUR

Evaluate methods to increase public awareness of the dangers associated with substance use/abuse, particularly to women, expectant mothers and newborns.

PRE-PREGNANCY	PRENATAL	BIRTH	NEONATAL	CHILDHOOD & ADOLESCENCE
This timeframe offers the opportunity to promote awareness of the effects of prenatal substance use among women of child-bearing age and their family members.	*This intervention point encourages health care providers to screen pregnant women for substance use as part of routine prenatal care and make referrals that facilitate access to treatment and related services for women who need those services.*	*Interventions during this timeframe incorporate testing newborns for substance exposure at the time of delivery.*	*Developmental assessment and the corresponding provision of services for the newborn as well as the family at this intervention point, immediately after the birth event, are the emphasis.*	*This timeframe calls for ongoing provision of coordinated services for both child and family.*

GENERAL CONSIDERATIONS

Addiction and drug abuse during pregnancy should be treated as a health issue since research shows universal criminalization has been ineffective.

Due to current data gaps, the North Dakota State Epidemiological Outcomes Workgroup (SEOW) should determine the best means and methods for developing short- and long-term data on the incidence and cost of Neonatal Withdrawal Syndrome/Neonatal Abstinence Syndrome (NAS).

The North Dakota Department of Health should explore mechanisms for recording data on the numbers of newborns born exposed to substances, the substances they are exposed to and the number diagnosed with NAS*.

Medical professionals should follow the current laws for testing, referring, follow-up and reporting pregnant women who are abusing alcohol or using controlled substances and for reporting substance exposed newborns.

State's attorneys and behavioral health professionals should evaluate the pros and cons of having an affirmative defense of periodic drug testing and consent to home visits in cases where criminal child abuse and neglect stems from a parent or caregiver's substance abuse.

*NAS: Neonatal Abstinence Syndrome (also known as Neonatal Withdrawal Syndrome)

	PRE-PREGNANCY	PRENATAL	BIRTH	NEONATAL	CHILDHOOD & ADOLESCENCE
POLICY					
SCREENING/ INTERVENTION		Medical providers of services to pregnant women should be trained about their testing, referring, follow-up and reporting responsibilities. Medical providers should develop consistent protocols for universal screening and testing of pregnant women.	Medical providers should develop consistent protocols for universal screening and testing of newborns.		
SERVICES	Health care providers should be informed of, and encouraged to refer patients to addiction treatment resources as necessary. A list of current addiction treatment resources should be made available to health care providers. Medical and behavioral health providers should be brought together to share information and strategies for integrating and coordinating treatment of patients.	Medical offices that provide care to pregnant women should develop protocols to identify patients who might be substance users/abusers and schedule appointments for them early in their pregnancies so they can receive information on the dangers of substance use/abuse as soon as possible. State agencies should work with medical professionals to develop standards of care for treating pregnant women who are addicted to various substances and to educate medical providers about these			Funding for home visiting should be expanded and available to more families. Residential pediatric care centers that provide wrap-around services for children with NAS* and their families should be established and maintained.

*NAS: Neonatal Abstinence Syndrome (also known as Neonatal Withdrawal Syndrome)

COMMUNICATION/ EDUCATION

PRE-PREGNANCY	PRENATAL	BIRTH	NEONATAL	CHILDHOOD & ADOLESCENCE
Develop education materials and an awareness campaign to educate women of childbearing age, as well as their significant others and families, about the dangers of substance use/abuse during pregnancy.	Law enforcement officers need education regarding the reporting of substance using/abusing pregnant women to county social services.		Hospitals and social service agencies should partner in the development of plans of safe care for each newborn born with prenatal exposure to substances, prior to discharge from the hospital following the birth. The plans should include educational materials on NAS* for parents and caregivers.	Information on the possible long-term effects of NAS* should be available to educators, health care providers, social workers and foster parents so they can identify children who may have been affected by exposure to substances in utero and who need additional educational and medical care during childhood as a result. County social services and direct service providers need training so they can better inform foster parents about care for substance exposed newborns. Social workers also need appropriate education materials and training presentations on NAS* that they can offer to foster parents. Juvenile Court personnel need education regarding the effects of prenatal exposure to alcohol and controlled substances, the risks to newborns suffering from NAS* and the risks associated with returning a substance exposed newborn to a home with a mother who is using substances without appropriate court-ordered safety and intervention services.

*NAS: Neonatal Abstinence Syndrome (also known as Neonatal Withdrawal Syndrome)

#11231

Overlapping Behavioral Characteristics & Related Mental Health Diagnoses in Children

Overlapping Characteristics & Mental Health Diagnoses	FASD	ADD/ ADHD	Sensory Int. Dys.	Autism	Bi-Polar	RAD	Depres-sion	ODD	Trauma	Poverty
	Organic	Organic	Organic	Organic	Mood	Mood	Mood	Mood	Environ	Environ
Easily distracted by extraneous stimuli	X	X								
Developmental Dysmaturity	X			X						
Feel Different from other people	X				X					
Often does not follow through on instructions	X	X					X	X	X	X
Often interrupts/intrudes	X	X	X	X	X		X			X
Often engages in activities without considering possible consequences	X	X	X	X	X					X
Often has difficulty organizing tasks & activities	X	X		X	X		X			X
Difficulty with transitions	X		X	X	X					
No impulse controls, acts hyperactive	X	X	X		X	X				
Sleep Disturbance	X				X		X		X	
Indiscriminately affectionate with strangers	X		X		X	X				
Lack of eye contact	X		X	X		X	X			
Not cuddly	X			X		X	X			
Lying about the obvious	X				X	X				
Learning lags: "Won't learn, some can't learn"	X		X			X			X	X
Incessant chatter, **or** abnormal speech patterns	X		X	X	X	X				
Increased startle response	X		X						X	
Emotionally volatile, often exhibit wide mood swings	X	X	X	X	X	X	X	X	X	
Depression develops, often in teen years	X	X				X			X	
Problems with social interactions	X			X	X		X			
Defect in speech and language, delays	X			X						
Over/under-responsive to stimuli	X	X	X	X						
Perseveration, inflexibility	X			X	X					
Escalation in response to stress	X		X	X	X		X		X	
Poor problem solving	X			X	X		X			
Difficulty seeing cause & effect	X			X						
Exceptional abilities in one area	X			X						
Guess at what "normal" is	X			X						
Lie when it would be easy to tell the truth	X				X	X				
Difficulty initiating, following through	X	X			X		X			
Difficulty with relationships	X		X	X	X	X	X			
Manage time poorly/lack of comprehension of time	X	X			X		X			X
Information processing difficulties speech/language: receptive vs. expressive	X			X						
Often loses temper	X		X		X		X	X	X	
Often argues with adults	X				X			X		
Often actively defies or refuses to comply	X				X			X		
Often blames others for his or her mistakes	X	X			X		X	X		
Is often touchy or easily annoyed by others	X				X		X	X		
Is often angry and resentful	X						X	X		

Cathy Bruer-Thompson, retired, Minnesota Organization on Fetal Alcohol Syndrome Board Vice-President, Special Needs Adoption Trainer cathybt@gmail.com 4/29/2016

With deep appreciation to the many who edited and contributed
www.mofas.org

References and Resources for

"Overlapping Behavioral Characteristics and Related Mental Health Diagnoses in Children"

Diane Malbin: Clinical social worker, program developer, nationally recognized trainer on FASD and consultant, co-founder of FASCETS (Fetal Alcohol Syndrome Consultation)

MOFAS (Minnesota Organization on Fetal Alcohol Syndrome): www.mofas.org

NAMI: National Alliance on Mental Illness - factsheets on mental health diagnoses, characteristics, medications, resources, local support groups for many mental illnesses

http://www.nami.org/Template.cfm?Section=By_Illness

- Attention Deficit Hyperactivity Disorder
- Autism Spectrum Disorder
- Bi-Polar Disorder
- Reactive Attachment Disorder
- Obsessive-Compulsive Disorder
- Post Traumatic Stress Disorder

Bruce D. Perry, M.D., Ph.D.: Senior Fellow of *The ChildTrauma Academy*

His neuroscience research has examined the effects of prenatal drug exposure on brain development, the neurobiology of human neuropsychiatric disorders, the neurophysiology of traumatic life events and basic mechanisms related to the development of neurotransmitter receptors in the brain.

Bessel van der Kolk, MD: clinician, researcher and teacher in the area of posttraumatic stress and related phenomena, Medical Director of *The Trauma Center,* a program of Justice Resource Institute

"Developmental Trauma Disorder: A New Rational Diagnosis for Children With Complex Trauma Histories," by Bessel van der Kolk, Psychiatric Annals, May 2005.

"Complex Trauma in Children and Adolescents," Cook, Spinazzola, Ford, Lanktree, Blaustein, Cloitre, DeRosa, Hubbard, Kagan, Mallah, Olafson, van der Kolk, 2005, Psychiatric Annals, pp. 390-398- Psychiatric Annals, May 2005.

Also "Attachment, Self-regulation and Competency (ARC)"

Mayo Clinic: Reactive Attachment Disorder Symptoms

http://www.mayoclinic.com/health/reactive-attachment-disorder/DS00988/DSECTION=symptoms

Walter D. Buenning, PhD, Licensed Psychologist

Reactive Attachment Disorder Child Checklist of Characteristics
http://www.reactiveattachmentdisordertreatment.com/childattachchecklist.pdf

Ruby K. Payne, Ph.D.: *A Framework for Understanding Poverty* and *Bridges Out of Poverty*

Research focuses on the effects of poverty on students, families, and communities and how to better understand and support people from all economic backgrounds

In addition this document was reviewed for accuracy by several Minnesota experts in Children's Mental Health and Fetal Alcohol Spectrum Disorders

2021 SENATE STANDING COMMITTEE MINUTES

Human Services Committee
Sakakawea Room, State Capitol

HCR 3011
4/5/2021

A concurrent resolution directing the Legislative Management to consider studying fetal alcohol spectrum disorders (FASDs), including treatment, services available, potential prevention, and whether existing policies for children and adults are appropriate.

Madam Chair Lee opened the discussion on HCR 3011 at 11:38 a.m. Members present: Lee, K. Roers, Hogan, Anderson, Clemens, O. Larsen.

Discussion Topics:

- Proposed amendment
- Bill action

[11:40] Pamela Sagness, Director, Behavioral Health Division, DHS. Provided the committee with proposed amendment (testimony #11357).

Senator Hogan moves to **ADOPT AMENDMENT** 21.3021.02001.
Senator K. Roers seconded.

Voice Vote – Motion passed

Senator Hogan moves **DO PASS, AS AMENDED.**
Senator Clemens seconded.

Senators	Vote
Senator Judy Lee	Y
Senator Kristin Roers	Y
Senator Howard C. Anderson, Jr.	Y
Senator David A. Clemens	Y
Senator Kathy Hogan	Y
Senator Oley Larsen	Y

The motion passed 6-0-0
Senator Anderson will carry HCR 3011.

Additional written testimony: N/A

Madam Chair Lee closed the discussion on HCR 3011 at 11:44 a.m.

Justin Velez, Committee Clerk

21.3021.02001
Title.03000

Adopted by the Senate Human Services Committee

April 5, 2021

PROPOSED AMENDMENTS TO ENGROSSED HOUSE CONCURRENT RESOLUTION NO. 3011

Page 1, line 1, after "studying" insert "and researching the impact of substance abuse and neonatal withdrawal syndrome, including a focus on"

Page 2, line 1, after "studying" insert "and researching the impact of substance abuse and neonatal withdrawal syndrome, including a focus on"

Page 2, line 5, after the second comma insert "incorporating the task force on substance exposed newborns recommendations as a result of 2015 Senate Bill No. 2367, as approved by the sixty-fourth legislative assembly,"

Renumber accordingly

REPORT OF STANDING COMMITTEE

HCR 3011, as engrossed: Human Services Committee (Sen. Lee, Chairman) recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** (6 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). Engrossed HCR 3011 was placed on the Sixth order on the calendar.

Page 1, line 1, after "studying" insert "and researching the impact of substance abuse and neonatal withdrawal syndrome, including a focus on"

Page 2, line 1, after "studying" insert "and researching the impact of substance abuse and neonatal withdrawal syndrome, including a focus on"

Page 2, line 5, after the second comma insert "incorporating the task force on substance exposed newborns recommendations as a result of 2015 Senate Bill No. 2367, as approved by the sixty-fourth legislative assembly,"

Renumber accordingly

A concurrent resolution directing the Legislative Management to consider studying and researching the impact of substance abuse and neonatal withdrawal syndrome, including a focus on fetal alcohol spectrum disorders (FASDs), including treatment, services available, potential prevention, and whether existing policies for children and adults are appropriate.

WHEREAS, FASDs are a group of conditions, including fetal alcohol syndrome, which can occur in an individual whose mother drank alcohol during pregnancy and which may include physical problems and problems with behavior and learning; and

WHEREAS, in 1993, the Legislative Assembly created the Fetal Alcohol Syndrome Center at the University of North Dakota School of Medicine and Health Sciences; and

WHEREAS, the Fetal Alcohol Syndrome Center publishes an annual report on the status of FASDs in the state; and

WHEREAS, although the prevalence of FASDs is 1 to 5 percent of live births in North Dakota, only 5 to 15 percent will be diagnosed with FASDs; and

WHEREAS, there is an increased cost of medical care services for a child with FASDs, with an annual excess cost for medical care due to FASDs of $4,403 per case, and the cost of inpatient medical care for each case of FASDs to age 18 being $95,034; and

WHEREAS, in addition to medical care, the cost to a family to care for a child with FASDs is $17,400 per year, including expenses for travel, meals and lodging, insurance deductibles, vacation and sick leave, child care, work-related costs, and deferred promotions; and

WHEREAS, although prenatal alcohol exposure often occurs with other substance abuse and often is not detected, of all the substances of abuse, alcohol produces by far the most serious adverse effects for the fetus; and

WHEREAS, if a woman has a child with FASDs and continues to drink, the woman has more than a 75 percent chance of having another child with FASDs;

NOW, THEREFORE, BE IT RESOLVED BY THE HOUSE OF REPRESENTATIVES OF NORTH DAKOTA, THE SENATE CONCURRING THEREIN:

That the Legislative Management consider studying and researching the impact of substance abuse and neonatal withdrawal syndrome, including a focus on FASDs, including treatment, services available, potential prevention, and whether existing policies for children and adults are appropriate; and

BE IT FURTHER RESOLVED, that the Legislative Management report its findings and recommendations, incorporating the task force on substance exposed newborns recommendations as a result of 2015 Senate Bill No. 2367, as approved by the sixty-fourth legislative assembly, together with any legislation required to implement the recommendations, to the Sixty-eighth Legislative Assembly.