



fact sheet

Who: A multi-sector action group formed by Rasmuson Foundation, the Alaska Mental Health Trust Authority, Mat-Su Health Foundation, State of Alaska-Department of Health and Social Services, and other stakeholders.

What: A solutions-focused effort to recover, reclaim, and restore the strengths of Alaska's families and communities by getting to the root causes of excessive alcohol consumption.

How: Focus on systems, policy, statutes and practices that will lead to long-term improvements.

Why: Alcohol use and abuse is the top health issue important to Alaskans.¹

The monetary impact of alcohol and substance abuse to the Alaska economy are approximately \$1.2 billion.²

Excessive alcohol consumption negatively impacts all Alaskans.

Activities to date:

Anchorage Daily News Journalism Project

Year-long journalistic investigation of the impact of alcohol on the state that will continue through June. Coverage from the series can be found at www.recoveralaska.org

Title IV Statute Review

Comprehensive review of the statutes that govern the licensing, sale, and distribution of alcohol in Alaska. We anticipate a package will be brought forth to the Legislature in 2015.

Adverse Childhood Experiences Study

With the Alaska Children's Trust, disseminate study findings and train a statewide speakers bureau on the ACE study.

Connecting Alaskans to Help

Seeking support for pilot implementation of referral and case management services for Alaskans seeking access to information on prevention and treatment for alcohol addiction.

Recover Alaska Dialogues

Face-to-face meetings with behavioral health providers representing veterans and military providers, state grantees, members of the faith-based community, primary care clinics, Alaska Native sobriety movement leaders and tribal behavioral health directors.

More information visit www.recoveralaska.org

¹ Healthy Alaskans 2020

² The Economic Costs of Alcohol and Drug Abuse in Alaska 2012, Alaska Mental Health Board & Advisory Board on Alcoholism and Drug Abuse.



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ALASKA'S NEWSPAPER

A WOMAN CAN DAMAGE

HER DEVELOPING FETUS

MORE PROFOUNDLY

BY DRINKING ALCOHOL

THAN BY SMOKING CRACK

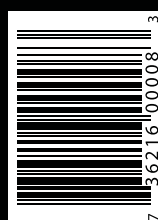
OR SHOOTING HEROIN.

THE DAMAGE IS PERMANENT,

AND IT CAN HAPPEN BEFORE

SHE EVEN KNOWS SHE'S PREGNANT.

See the first of two parts on Page A7



‘Fetal Russian Roulette’

1. SUSAN ESSARY

About the time of her divorce, Susan Essary started meeting friends for beers and whiskey on the weekends.

She normally only drank on holidays, Essary said, but two cans of Miller and two shots of Jack Daniels made it easier to talk. She vented about co-workers, her ex’s nosy family and the tiresome queasiness that gripped her each day after work.

“I could bring up things that really bothered me,” she recalled.

Just 23, Essary wasn’t alarmed to feel sick. Everyone seemed to be trading flu viruses at the hospital where she worked as a nurse’s assistant, preparing operating tables. The graveyard shift and sunrise dinners upset her stomach. She had just filed paperwork to end a gut-wrenching marriage with a man who had choked and punched her, and was now bound for prison.

Essary’s mother suspected something else. She noticed a familiar rhythm to her daughter’s nausea and mood swings.

“Go to the store and pick up a pregnancy test,” she texted.

Essary, who had been using birth control pills for months, told her mother she was crazy. “She just wanted another grandbaby.”

Yet that night in the bathroom, Essary stared at a home pregnancy test as two blue lines appeared. Positive.

Doctors would tell Essary that antibiotics prescribed for an infection likely caused her birth control to fail. That discovery came much later.

For now, she pulled the second pregnancy test from the box. A shapeless worry began to form.

“That’s actually when it came to my mind — about the drinking,” she said.



Susan Essary said she was using birth control and drank with friends while she was unknowingly pregnant with her son, Elijah. It wasn’t until her son was in kindergarten that he was diagnosed with a fetal alcohol spectrum disorder.

Nearly half of Alaska women who become pregnant did not plan to have a baby. Many women don’t know that even moderate drinking can do irreversible damage to a child from conception to birth, beginning well before they realize they are pregnant.

Others know the risk and want to stop drinking, but can’t.

As a result, thousands of people living in Alaska today were born with lifelong, irreparable brain damage caused by alcohol exposure in the womb. More than 150 more are born each year. Some will cost the public millions of dollars in social services, hospital bills, court fees, prison expenses and foster care over the course of their lives.

This is the story of what happens to babies exposed to alcohol during pregnancy, told by four Alaska mothers who hope to help other women avoid repeating their mistakes.

First, the science.

The trouble begins within days of conception, as alcohol consumed by the mother kills cells destined to become the building blocks of her baby’s brain, organs and central nervous system. Her child may suffer memory lapses, learning disabilities and a range of behavioral problems, including dangerous impulsivity.

In the most serious cases, the disability is called fetal

alcohol syndrome. It punches holes in the brain’s ability to process information and reshapes the child’s face.

While most states do not reliably track the number of children born with FAS or other fetal alcohol spectrum disorders, health officials suspect hard-drinking Alaska has the highest rate in the country. Women of child-bearing age here are 20 percent more likely to binge drink than the national average, according to the national Centers for Disease Control and Prevention.

After a decline in FAS cases in the state, the Division of Public Health more recently reports a puzzling trend of Alaska women increasingly saying they drank while pregnant.

“At the grocery store I see the kids running up and down the aisles and I see it in their faces,” said Gayle Young, coordinator for the FAS diagnostic team in Sitka.

At the current rate of testing, most children and especially most adults with an alcohol-related birth defect will never be diagnosed. Yet Young recognizes the hallmark facial features of FAS on parents and grandparents too, she said, and in white-collar offices and corporate board rooms around Alaska.

“It’s a silent epidemic,” she said.



- Prenatal alcohol exposure is considered the Western world’s leading cause of “intellectual disability,” which used to be called mental retardation. It is completely preventable.

- Each child born with fetal alcohol syndrome costs the public \$1 million to \$4 million in health care and social services over a lifetime. In Alaska, that’s about 15 children each year.

- It costs the public 30 times more to raise a child with FAS than to prevent a second FAS birth by helping a mother get sober.

- One to 5 percent of Americans suffer some form of FASD. Alaska rates are believed to be far higher than the national average.

- Nationwide, the women most likely to drink during child-bearing years are white, in their 30s and 40s and college-educated.

Find our sources for this information on Page A-10.

What separates FASD from FAS?

FASD stands for fetal alcohol spectrum disorders, an umbrella term that refers to a variety of disabilities and birth defects caused by a mother’s alcohol consumption while pregnant.

FAS stands for fetal alcohol syndrome, a specific medical condition that includes a trio of distinct facial features, undersized height and weight and damage to the central nervous system. It is considered the most severe of the fetal alcohol spectrum disorders.

**State of
intoxication**
ALASKA AND ALCOHOL
adn.com/alcohol

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TELL US YOUR STORY:
Fetal alcohol spectrum disorders affect all Alaskans. If you would like to share your story on this topic, have ideas for ways that Alaska can address FASD or help people with the disability, email us at, alcohol@adn.com.

JOIN THE CONVERSATION
on Facebook and Twitter
(use the hashtag #FASD).

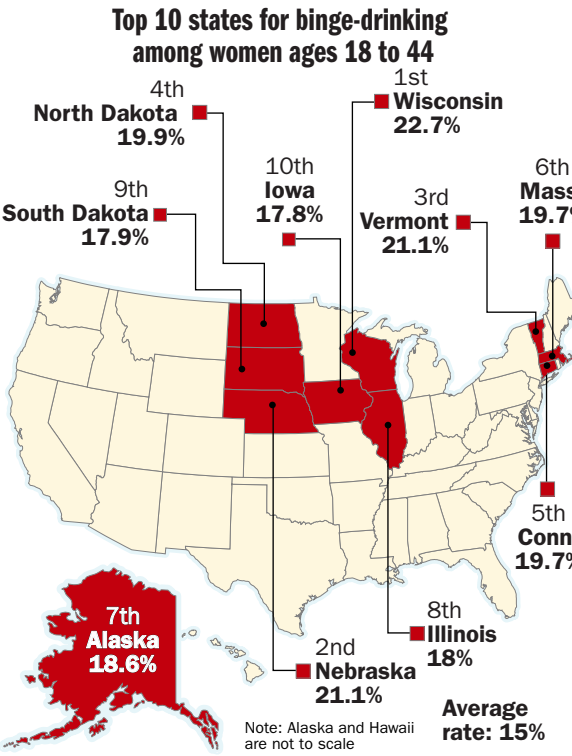
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Jamie Gagnon says she struggled with alcoholism and a difficult home life while she was pregnant with her second daughter. Now she says her daughter, who was diagnosed with an FASD in 2012, inspires her to stay away from alcohol. She has been sober for nearly five years, she says.

The hardest-drinking women

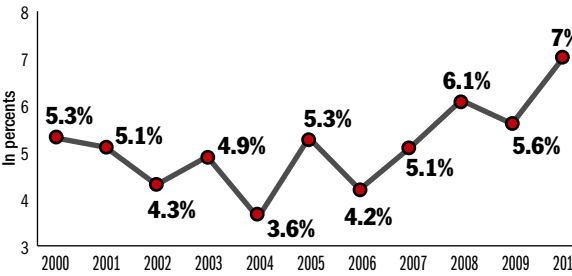
Alaska has one of the country's highest rates of binge drinking among women, which greatly increases the risk of prenatal brain damage in their children. Women of child-bearing age drink harder here than in all but six states.



Source: Centers for Disease Control & Prevention. Figures are for 2010. For women, binge drinking is defined as four or more drinks on any one occasion during the prior 30 days.

Drinking during the last trimester

Shows percentage* of Alaska mothers who say they drank in the last three months of pregnancy



*Data based on an ongoing random survey of mothers who recently delivered a live birth, conducted for the CDC.

Source: Centers for Disease Control & Prevention, Pregnancy Risk Assessment Monitoring System

PAMELA DUNLAP-SHOHL / Anchorage Daily News

2. JAMIE GAGNON

Jamie Gagnon knew drinking while pregnant was dangerous. Her sister-in-law had warned her about fetal alcohol syndrome. Even though she had once been fired from a restaurant for drinking cooking vodka as a teenager, she stayed dry all through her first pregnancy.

When Gagnon later moved to Alaska and divorced, the binging still felt under control. That changed when Gagnon began dating a neighbor in her South Anchorage apartment, she said. He was always angry, it seemed, but she married him anyway.

Usually her clothes hid the bruises, she said. Once a beer drinker, she progressed to buying a gallon of rum every weekend. She cured hangovers with more booze. This time, she figured, pregnancy was no reason to stop drinking. Afraid to have her husband's baby, Gagnon had been planning an abortion. When Anchorage police watched her Oldsmobile Bravada bounce across a Dimond Boulevard median, it led to a charge of drunken driving. Her blood-alcohol level was more than twice the legal limit.

The judge told Gagnon, then 24, to stay away from liquor. She showed up to court smelling like Captain Morgan's.

Gagnon walked into her cell three months pregnant. By the time she left prison, she had abandoned thoughts of terminating the pregnancy. She now thought of her unborn daughter as a guardian angel.

"I'm in jail and she was like my best friend," said Gagnon, who is now 35 and will be five years sober in March. "I wasn't alone," she said. "It's been that way ever since."

Although rates of FAS are highest in rural corners of the state, the disability crosses all races, cultures and regions. Nationwide, it's white, college-educated women in their mid-30s and 40s who are most likely to drink during pregnancy, the CDC says.

Contrary to conventional wisdom, "this is not just a problem in the Alaska Native population. It's not just a problem in Alaska. It's a problem anywhere people drink," said Deb Evensen, an FAS expert for the Anchorage School District.

Just two generations ago, the disability went undiagnosed by modern medicine. Though scholars across history had speculated about a link between alcohol and "withered" newborns, University of Washington Medical School researchers first named and identified FAS in 1973.

"Clear references to the dangers of drinking alcohol while pregnant date back to biblical days," said Dr. Susan Astley, a University of Washington fetal alcohol syndrome expert and director of the Washington State FAS Diagnostic & Prevention Network.

"Behold, thou shalt conceive, and bear a son; and now drink no wine nor strong drink," warns the King James Bible, in Judges 13:7.

Today FAS is considered the leading cause of "intellectual disability," what used to be called mental retardation, in the Western world. Although wholly preventable, FAS is as common as autism in the United States.

The availability and toxicity of alcohol to a developing fetus both fuel the problem.

Many substances, including most illegal drugs, can damage an unborn child. The worst of these — the ones that can cause serious malformations in developing fetuses — are called teratogens. Lead, mercury and radiation are all teratogens.

Alcohol is a teratogen and by far the one most commonly encountered by humans. Alcohol is more likely to cause brain damage and lifelong behavior problems



Evensen

in unborn children than either crack cocaine or heroin, which can also harm the baby, according to The Institute of Medicine.

"The legal drug is worse than the illicit drugs in terms of its impact on a fetus," said Marilyn Pierce-Bulger, an Anchorage nurse practitioner who diagnoses alcohol-related birth defects in Alaska children. "(Alcohol) kills and alters cells in a way that these other things can't."

The damage can begin immediately after conception, when heavy drinking can kill the just-fertilized egg.

Six to nine days after conception, the developing embryo anchors to the wall of the mother's uterus. Now connected by the umbilical cord, the once-floating embryo and its mother share a common blood supply. From now until birth, for nine months, the mother and baby will drink — or not drink — together.

During the third week of gestation, about 17 to 21 days after conception, the embryo is the size of the tip of a pen, yet the brain, spinal cord and other organs are forming.

During this narrow span of days, alcohol can alter the blueprint for a child's face, resulting in narrow eye openings, a thin upper lip and a flattening of the philtrum (the indentation between the nose and upper lip).

"Nothing except alcohol will cause these three features together," Pierce-Bulger said.

At this point, less than a month after conception, most women still wouldn't realize they're pregnant.

"Those facial features are forming right around the time she may miss a (menstrual) period," said Pierce-Bulger, who worked for decades as a nurse midwife at the Alaska Native Medical Center. "Most of the women that I know and have worked with for 30 years aren't paying attention (this early in a pregnancy)."

The size of an embryo at 17 to 21 days.

See next page

Diagnosing FAS and FASD

Four experts work as a team to diagnose a child with fetal alcohol syndrome. A psychologist, a medical professional, a speech pathologist and an occupational therapist examine the child in a process that can last from hours to months.

Diagnosing FAS is more complicated than simply looking for physical features caused by alcohol, although those traits are crucial to a diagnosis. Children with FAS are smaller than their peers and have unique facial features, including small eyes, a thin upper lip and a smooth philtrum (the groove between the nose and upper lip).

"... Nothing except alcohol will cause these three fea-

tures together," said Marilyn Pierce-Bulger, a nurse practitioner and member of Assets Inc., one of six diagnostic teams across the state.

Diagnostic teams here use facial recognition software created by the University of Washington to help determine whether a child meets the criteria for fetal alcohol syndrome.

Most children damaged by a pregnant mother's drinking do not have full FAS. Some patients with a less visible fetal alcohol spectrum disorder may actually have more severe behavioral or learning disabilities than those with full FAS.

TO LEARN MORE about the diagnostic process, go to www.depts.washington.edu/fasdpn



3. HEIDI ANNE CASE

Raised a member of the Church of Jesus Christ of Latter-day Saints in Utah, Heidi Anne Case was married at 19. The Mormon faith emphasizes teetotaling and abstinence before marriage. She never learned much about dating or drinking.

After her divorce in 2004, at age 27, Case test-drove a new life. First there was the guy at the pool hall and a one-night stand. “I know his name, and that’s about it,” she said.

Then the three-day cruise along the lagoons and sun-baked cities of the Mexican Riviera. Case read magazines and watched the waves with her best friend, always with a Malibu Rum and Coke in hand.

“We actually were on the ‘party boat,’ so that made it even worse. The drinks are free,” she said.

About two weeks after the cruise, a bolt of realization struck her: When was her last period? She raced to a dollar store and bought a pregnancy test.

“I had no clue, first of all, that I was pregnant, and second of all, that FAS even existed,” Case said. “It’s against our religion, basically to drink and be that type of person.”

Already the mother of four healthy children, she knew how a pregnancy ought to feel. This one was different. She made an appointment for an abortion, which was also against her religion — and something she had never thought she could do. “That’s when they told me I was too far along.”

She had passed her first trimester. Six weeks before her due date, the doctors urged her to induce delivery because the baby was showing “a failure to thrive.”

“He had stopped growing,” Case said.



Heidi Case says she took an “FASD 101” class while living in Alaska. She said it was the first time she had heard the term. “When that class got over, I just lost it. It was then that I realized that this could be what’s wrong with Jacob.” Heidi and Jared Case uprooted their family from Utah and moved to Alaska in 2011 to seek psychiatric care for their son. While living in Wasilla, Heidi began to learn about the effects her drinking had on Jacob while she was pregnant. Jacob was diagnosed with partial fetal alcohol syndrome in 2012.

By the fourth week of pregnancy, a baby’s rapidly developing heart is beating. Alcohol exposure can cause either too little or too much vitamin A, leading to heart valve abnormalities and a greater risk of heart disease.

All areas of the brain are vulnerable. The corpus callosum — the bundle of fibers responsible for communication between the left and right halves of the brain — can under-develop, leading to a slew of behavioral and brain problems.

Damage to the fetal central nervous system can leave children overwhelmed by their senses, making bright lights, loud sounds or even the touch of certain clothing and fabrics unbearable.

A recent study by the University of California-San Francisco found that children with such sensory processing disorders were likely to have abnormal “white matter,” meaning nerves damaged by alcohol exposure in the womb.

Many of the most serious defects in the heart, organs and limbs of an alcohol-exposed fetus occur in the first eight weeks. But a mother’s later drinking can damage the fetus’ central nervous system, meaning the

brain and spine, at any point during the pregnancy. It also leads to a physically smaller child.

Kids with fetal alcohol syndrome are generally shorter and weigh less than 97 percent of their peers.

The brain of a child with FASD is like a jigsaw puzzle. Pieces are missing, but no one knows which ones. Family genetics, a mother’s diet, how much alcohol the mother drank and what parts of the brain and body were forming at the time all play a role in whether the baby will develop fetal alcohol syndrome, some less visible disability or no measurable disability at all.

It’s fetal Russian Roulette.

Studies of non-identical twins exposed to alcohol in the womb have found that one sibling can be diagnosed with fetal alcohol syndrome while the other shows no serious damage.

As an entirely avoidable birth defect, FASD is not hereditary. A girl born with a fetal alcohol spectrum disorder will not give birth to a baby with FASD unless she also drinks while pregnant.

See next page

‘HOW MUCH CAN I DRINK?’

Confused as to whether any amount of alcohol is safe for an expecting mom to drink? You’re not alone.

Recent, well-publicized studies from researchers in Denmark downplay the risks of consuming alcohol during pregnancy.

Such a suggestion is wrong, according to Dr. Susan Astley, a University of Washington fetal alcohol syndrome expert and director of the Washington State FAS Diagnostic & Prevention Network.

“At the moment there’s a lot of press misunderstanding (of) a handful of research studies that have gone to publication that insinuate a little bit of drinking is not only OK but is beneficial to the developing fetus,” she said. “We contend that the reason the children in these studies do not appear to be harmed by alcohol is because the children were too young to measure the full impact alcohol may have had on their brains.”

Children damaged by prenatal alcohol exposure do deceptively well in their preschool years. The full effect of the damage caused by their mothers’ drinking while pregnant will not be evident until their adolescent years, she said.

Some doctors say there is little reason to believe an occasional glass of wine or a margarita consumed before a woman knows she is pregnant could do noticeable damage to a child. A “significant” number of people whose mothers drank during pregnancy have no measurable fetal alcohol spectrum disorder, said Dr. David Sperbeck, director of psychological services for North Star Hospital in Anchorage.

Yet a review of 2,600 children diagnosed with full fetal alcohol syndrome in Washington state found that one in every seven kids with FAS had been exposed to just one to eight drinks a week while in the womb. In 2000, researchers in Berlin, Tokyo and St. Louis found that exposing infant rats to a single dose of alcohol — equivalent to two times the legal limit over four hours — caused “considerable damage” to the developing brain.

The harm done to each child depends on the mother’s genetics, the child’s genetics and what parts of the brain and body were developing when she drank.

Doctors can diagnose a child based on the hallmark facial features of FAS alone but it is difficult to predict or measure the severity of brain injury and potential behavior problems until the child is 6 years old or older. It’s harder still to determine whether a child has alcohol-induced brain damage without visible, physical signs of disability. Such children far outnumber those with FAS but they may have just as much brain damage, if not more, than children whose facial features hint at the injury to their brains.

“They don’t have the outward signs, they don’t have the face,” said Marilyn Pierce-Bulger, a nurse practitioner who diagnoses children for fetal alcohol spectrum disorder in Anchorage. “It’s the hidden disability.”

The Surgeon General in 2005 urged women who are pregnant or may become pregnant to stop drinking in order to prevent alcohol-related disabilities in their unborn children.

Prenatal Development

Drinking alcohol while pregnant can cause lifelong brain damage and other birth defects in a baby.

Some researchers disagree on whether small amounts of alcohol can cause measurable damage, but the Surgeon General warns that no amount has been proven safe for a pregnant mother. For now, scientists are still learning exactly how and when alcohol exposure injures a developing embryo or fetus. Here’s some of what they know so far:

ZYGOTE TO EMBRYO

- During the first two weeks after fertilization, there is a chance heavy drinking will kill the developing embryo by preventing proper implantation in the uterus. However, alcohol exposure is not likely to cause birth defects at this pre-embryo stage.

EMBRYONIC PERIOD

- Early embryos that develop major malformations sometimes die in the first six to eight weeks of gestation.
- A trio of subtle facial features, caused by alcohol exposure, may begin to form at about 17 to 21 days. They include: small or narrow eyes, a thin upper lip and a smooth philtrum (the vertical groove between the upper lip and nose).
- Between days 15 and 60, alcohol is more likely to cause major birth defects than later in the pregnancy. During this period, deformities of joints, limbs and fingers may occur.
- Heart defects, such as ventricular septal defect, a hole or holes in the wall that separates the left ventricles of the heart, may occur. This can lead to a fast heart rate, failure to gain weight and shortness of breath.
- The brain is vulnerable to alcohol throughout gestation. At six to seven weeks, the corpus callosum or “white matter” that bridges the left and right side of the brain is particularly vulnerable to alcohol and can become under-developed.

FETAL PERIOD

- Specific birth defects to organs are not normally expected, although alcohol can continue to damage the brain and central nervous system at any point from now until birth.
- The fetus may grow more slowly and emerge undersized during this period.
- Asymmetric growth restrictions, meaning a normal-sized head but smaller-than-normal abdominal cavity, may occur because of heavy drinking during the third trimester. The fetus protects brain and heart growth at the expense of less vital processes like digestion.
- There is no point during development when a mother’s drinking lacks potential consequences for the baby.

Source: Adapted from Moore, K., & Persaud, T. (1998); Wendy Chung, M.D. Ph.D., Columbia University “Teratogens and Their Effects” National Library of Medicine: <http://www.nlm.nih.gov/medlineplus/ency/article/000911.htm>, <http://embryo.asu.edu/pages/developmental-timeline-alcohol-induced-birth-defects>, <http://embryo.asu.edu/pages/developmental-timeline-alcohol-induced-birth-defects>

PAMELA DUNLAP-SHOHL / Anchorage Daily News



Helen Benson takes a moment to herself on her front steps in December. Benson had been dealing with behavior challenges in her daughter, Serenity. Benson attributes her daughter's behavior to her partial fetal alcohol syndrome. "I wish I could say that every time I deal with it, it gets a little easier to deal with," Benson said. "But every single time I have to deal with one of these episodes it wipes me out. It's really exhausting."

About State of Intoxication

The State of Intoxication series is a year-long reporting project examining the social costs of alcohol use and abuse in Alaska. The series is controlled and directed by the Anchorage Daily News. It is financially supported by a grant from the Recover Alaska Media Project fund at the Alaska Community Foundation. Contributors to the fund are the Alaska Children's Trust, the Alaska Mental Health Trust Authority, Bristol Bay Native Corp., the John S. and James L. Knight Foundation, Providence Health & Services Alaska, the Mat-Su Health Foundation, Wells Fargo and the Rasmuson Foundation.

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4. HELEN BENSON

"I drank as an escape. I knew it wasn't good for my baby," said Helen Benson, who began using cocaine at 16. By her late 20s she had graduated to smoking crack. In 2006, at age 30, she became pregnant. The baby's father, tall and blonde with ice blue eyes, seemed nice enough at first, she said. After a few months, Benson heard rumors he was cheating and the couple began to squabble constantly — about money, house-cleaning, his drinking. Mutual drug use amplified the fighting. Sometimes the boyfriend got high on meth and slammed her into walls. The sex turned violent, with his big hands at her throat. Benson began missing her periods. Pregnancy made the relationship worse. "He fed me (crack) like it was candy," she said. "He hoped I would miscarry." Alcohol was always easier to get than drugs, so Benson binged on Jack Daniels and Coke more often than crack cocaine. She drank until she threw up, then drank some more. It was her boyfriend's mother, in a series of furtive phone calls, who convinced her to escape the relationship and get sober. "She said, 'You're carrying my grandchild, please give this baby a chance.' " Benson fled to a domestic violence shelter. Six months pregnant, she began meeting with an obstetrician. As her mind cleared, Benson began to wonder: Would her daughter be born with disabilities? Would she look different than other children? Would she be OK? There was nothing to do except stop drinking and using drugs. "She changed my life," said Benson. "If it wasn't for her, I can't say that I'd still be here. She was my motivation for sobering up." Benson named her Serenity.

Next: In Part 2, on Tuesday, meet the children.

Photographer Marc Lester contributed to this story. Reach Kyle Hopkins at 257-4334 or khopkins@adn.com, and Marc Lester at mlester@adn.com. For Twitter updates: twitter.com/adn_kylehopkins and twitter.com/marclesterphoto.



If you think FASD doesn't affect you and your family, Deb Evensen wants you to think again.



Evensen has been educating Alaskans about fetal alcohol spectrum disorders for more than 30 years. She works with school districts and organizations across Alaska and the U.S. to address the issue. In this video, she explains the five things everyone should know about FASD.

"We cannot deal with bullying and violence in schools," recidivism in the correctional system or dropout rates until the community looks at the number of kids prenatally exposed to alcohol, she says.

"It's the elephant in the living room, the whale in our umiak."

Autism or FASD?

Autism and fetal alcohol spectrum disorders are different disabilities with some similar symptoms. The causes of autism are not fully known, though most scientists agree genetics plays a role. Fetal alcohol spectrum disorders, including fetal alcohol syndrome, can only be found in children whose mothers drank during pregnancy. The problems are about equally common, estimated to affect about 11 out of every 1,000 children, according to the federal Centers for Disease Control and Prevention. A child can be diagnosed with both an FASD and autism, although sometimes children whose mothers drank during pregnancy are wrongly assumed to be autistic. Children with FASD may be sociable and outgoing, while autistic children are often aloof and prefer to be alone, for example. While FASD occurs in boys and girls at roughly the same rate, boys are four times more likely to be diagnosed as autistic. Both problems are incurable developmental disabilities, though friends and family members can help afflicted children live rich, happy lives. Here are the symptoms of each disorder, and how they overlap.

- Children with autism may:

 - Have difficulty relating to others in a meaningful way
 - Demonstrate restricted patterns of behavior, interests and activities
 - Speak in a robotic, formal way
 - Show ritualistic behaviors
 - Have trouble expressing humor
- Children with FASD may:

 - Feel different from other people
 - Experience disturbed sleep
 - Be indiscriminately affectionate with strangers
 - Lie about the obvious
 - Have an increased startle response
 - Develop depression, often in teen years
 - Have difficulty initiating activity or following through
 - Manage time poorly or lack comprehension of time
 - Actively defy or refuse to comply
 - Act touchy or easily annoyed
 - Become angry and resentful
- Children with either autism or FASD may:

 - Show developmental dysmaturity
 - Interrupt or intrude on others
 - Act without considering consequences
 - Have difficulty organizing tasks and activities
 - Have difficulty with transitions
 - Be impulsive, hyperactive
 - Avoid eye contact
 - Not be cuddly
 - Chatter incessantly or have delayed speech
 - Be emotionally volatile or exhibit wide mood swings
 - Have problems with social interaction
 - Have an over- or under-sensitive sense of touch
 - Struggle to understand cause and effect of their actions
 - Show exceptional abilities in a single area, such as music or math
 - Have difficulty with friendships

Sources: Cathy Bruer-Thompson, Adoption Training Coordinator, Hennepin County, Minn., via Assets Inc.; Minnesota Organization of Fetal Alcohol Syndrome.

DEFENSE CUTS PLAN A MIXED BAG FOR BASES

Some take heavy hit, while others spared; lawmakers are raising questions.

By JAMES ROSEN
McClatchy Washington Bureau

WASHINGTON — Sweeping budget and personnel cuts proposed Monday by Defense Secretary Chuck Hagel would hit some military bases hard while protecting others.

With the Army targeted to lose as many as 80,000 active-duty troops from its current 520,000-strong force, reaching its smallest size since before World II, major installations from Fort Jackson, S.C., to Fort Hood, Texas, could see their operations scaled back significantly.

The proposal to shrink the world's mightiest military force comes as the United States seeks to redefine its role on the world stage, with the Iraq war over and U.S. combat engagement in Afghanistan winding down, a two-front strategy involving lengthy occupations that severely tested military capabilities. It also reflects the competing demands of spending restraints, national security and politics.

Eliminating two dozen A-10 attack planes at Whiteman Air Force Base near Kansas City, for instance, is part of a broader move to retire all of the aging Warthogs, saving the Pentagon several billion dollars. But lawmakers from Missouri

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NATION & WORLD NEWS

AG seeks rule on cyberattack notices

After a spate of large cyberattacks on retailers, Attorney General Eric H. Holder Jr. urged Congress to adopt a national standard for notifying consumers of a breach. **Page A-3**

Ukraine faces major economic challenges

With a manhunt underway for the deposed Ukrainian president, the country's most pressing problem is a fast-approaching economic disaster that they cannot solve without international assistance. **Page A-4**

A silent epidemic



Helen Benson and her daughter, Serenity, hug at home in December. Helen knows her drinking during pregnancy caused the challenges her daughter faces. "I think I dealt with the guilt when I was first getting clean," she says. "I don't have time to feel guilty, because if I take time to feel guilty, I'm taking time away from my kids."

PART 2

Such an easy baby. Serenity only cried when someone held her. She looked healthy enough, her mother thought. A nine-pound newborn with a wisp of blond hair and cloudless blue eyes. But so quiet.

What infant doesn't wail to be fed or changed or coddled, her mother, Helen Benson, wondered.

"I knew something was wrong from the get-go," she recalled.

Benson asked her family doctors about it in the small South Carolina town where Serenity was born. Benson had used drugs and drank until she blacked out throughout the first six months of pregnancy, she confided to them.

Don't fret, the doctors said. You must be a good mom to have such a quiet baby.

It wasn't until Benson moved to Alaska that she learned her baby was born with a fetal alcohol spectrum disorder (FASD), one of a collection of permanent disabilities caused by exposure to alcohol in the womb.

Like mercury, lead and radiation, alcohol is a teratogen, which means it causes abnormalities in the body and brain of an embryo or fetus. While some researchers disagree on whether exposure to a small amount of alcohol can cause measurable damage to a child, no amount of drinking, at any time during pregnancy, has been proven safe.

If a mother binges early in pregnancy, alcohol can re-form a child's face, causing a smooth philtrum (the vertical groove between the upper lip and nose), a thin upper lip and small eyes. As the child gets older, he or she may exhibit a variety of behavioral issues, from irritable aggression to a risky eagerness to please. But for most, their disability is not ob-

vious.

As many as nine in 10 children with an FASD are diagnosed with something less visible than full fetal alcohol syndrome. That diagnosis specifically requires that the child have the hallmark facial features and be under-sized in height and weight. Even so, FASD children may suffer behavior and learning problems as severe as those with full FAS, or even more so.

A child with an FASD can suffer damage to parts of the brain that determine intelligence, memory, language ability, motor skills and senses like touch and hearing.

Life for an FAS or FASD child can be even harder if parents and teachers don't understand their affliction.

"Their nervous system and their brain is working differently, but they look like regular kids on the outside," said Dr. Susan Astley, a University of Washington fetal alcohol syndrome expert who has diagnosed almost 3,000 people over 20 years. "We'd never punish the blind kid for not being able to see the blackboard (just) because their disability is visible to us."

See Page A-5, ALCOHOL



ON SUNDAY, we told the stories of four mothers who drank during their pregnancies. This is the story of their children: Serenity, Elaine, Jacob and Elijah. All four share three truths: Their disability was caused by alcohol, it was 100 percent preventable and it will influence every aspect of their lives for as long as they live.

By
KYLE HOPKINS
and
MARC LESTER

Photos and
videos by
MARC LESTER

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Justices to weigh EPA move to regulate greenhouse gases

By DAVID G. SAVAGE
Tribune Washington Bureau

WASHINGTON — The Obama administration's drive to regulate greenhouse gases could hit a snag at the Supreme Court this week as industry groups and Republican-led states ask justices to block what they call a "brazen power grab" by the president's environmental regu-

lators.

Amid legislative inaction in a deadlocked Congress, the Environmental Protection Agency adopted regulations in 2011 that require new power plants, factories and other such stationary facilities to limit carbon emissions.

The agency said the rules were justified by a 2007 Supreme Court ruling that held

that carbon dioxide, methane and nitrous oxide — seen as the chief culprits behind a warming planet — are air pollutants subject to EPA regulation under the Clean Air Act.

In that decision, four conservative justices dissented, insisting that the law covered only air pollutants that make

See Back Page, EMISSIONS

Bias found in Syria war postings

Scholars say social media are edited to reflect specific view.

By LAUREN KIRKWOOD
McClatchy Washington Bureau

WASHINGTON — YouTube videos and posts on Facebook and Twitter have made scenes from Syria's civil war accessible to audiences thousands of miles from the conflict. But the version of events disseminated by social media is not a completely accurate picture

of the war, according to a report from the congressionally funded U.S. Institute of Peace.

After reviewing more than 38 million Twitter posts about the Syrian conflict, a team of Middle East scholars from The George Washington University and American University concluded that rather than an objective account of what's taken place, social media posts have been carefully curated to represent a specific view of the war. It said the skewing of the social media

view of the conflict has been amplified by the way more traditional news outlets make use of the postings — for example, passing along social media posts written in English over those written in Arabic.

The analysts studied tweets that mentioned Syria in English or Arabic from the start of 2011 through April 2013. They then analyzed how "traditional" forms of media,

See Back Page, SYRIA

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1. JACOB, AGE 9

Heidi Case could tell her 9-year-old was in a bad mood. He'd come home with a teacher's note saying he'd been hitting himself at school, then he disappeared to play with the new air hockey table in the basement of the family's 4,800-square-foot home.

The playroom hummed with the activity of his five rambunctious siblings. Sometimes Jacob's older brother let him score a point in hockey, but sometimes not. Jacob's irritation boiled. Everyone seemed to be teasing him.

"Shut up!"

Just 52 pounds and bone thin, Jacob's body is always in motion. His piercing scream erupted without warning.

"Shut up! Shut up! Shut up!"

Jacob's brothers and sisters ignored the yelling. Heidi noticed that he was crumbling crackers over the new table. When she told him to stop eating there, he balled his hand into a fist as if to hit her. It wouldn't have been the first time.

Jacob's sisters hadn't given him his medication for attention deficit hyperactivity disorder that morning. (ADHD is a common co-occurring problem for children with FASD.) That explained a lot, Heidi said. The air hockey game ended with his brother scoring the winning point. Jacob picked up the puck, whipped it across the room and stomped upstairs.

No one tried to coax him into taking a bath. Jacob can't stand the feel of a towel on his skin. He doesn't like water to touch his face.

Upstairs, Heidi leaned over the marble kitchen counter and held her head in her hands. She'd been having headaches all day. Jacob finally calmed down at dinner, becoming groggier as he ate his chicken soup.

The meds are finally kicking in, his mother said.



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MARC LESTER / Anchorage Daily News
Heidi Case removes her son, Jacob, from the dinner table after he refuses to take a bath. Because of Jacob's sensory disorder, he dislikes the feel of water on his face or the touch of a towel on his skin.

Heidi Case is now 37. She became pregnant with Jacob shortly after she divorced her husband, Jared. The couple have since remarried, but at the time she binge drank for the first time in her life. She learned about the pregnancy only after returning to her home state of Utah from a "party boat" cruise to Mexico.

The father, a one-night stand, offered to pay for an abortion, but by then it was too late.

"It's not always alcoholics who have these children with FASD," she said. "It's people like me who went on a cruise and had a little fun and now, not only are we paying for it as a family, but I have a son who is paying for it for the rest of his life."

At birth, Jacob was an under-sized preemie laboring to breathe. He spent 10 days in the neonatal intensive care unit.

Already a mother of four, Heidi recognized that he was different. Jacob didn't sit up until he was almost a year old. He didn't walk until he was 18 months.

"Between 3 and 4, when he started doing preschool, we noticed how aggressive he was," she recalled.

His brother, three years older, seemed scared of him. One day Jacob arrived home in a police car after menacing a neighbor with a knife. "He used to threaten he was going to kill us in our sleep," she said.

Desperate for help, Heidi and Jared heard that Alaska offered better psychiatric care and residential treatment for children than Utah. They moved to Wasilla, and Jacob spent months in treatment while one of the state's six FAS diagnostic teams examined him and rendered a diagnosis of partial fetal alcohol syndrome.

None of the couple's other children have an alcohol-related disability. Before coming to Alaska, Heidi had never heard of fetal alcohol syndrome, she said. She simply assumed her son was spoiled.

"The doctors always tell you, 'Don't drink when you're pregnant.' But what they don't tell you is why," she said.

The Cases are now intimately familiar with the effects of alcohol exposure in the womb, how it can damage a child's developing nervous system, blocking or delaying important signals from reaching the brain, creating a traffic jam of impulses and information known as sensory processing disorder.

People with a fetal alcohol spectrum disorder can have an underdeveloped sense of touch or an unusually high tolerance for pain.

Others can be hypersensitive: an affectionate caress or reassuring touch is something to be avoided or endured; a particular fabric or the tag of a T-shirt feels unbearable.

Such hypersensitivity can be traced to a bundle of nerves that carries signals between the two halves of the brain, coordinating movement, interpreting sensations and helping process complex information.

The brain of a child with an FASD can be overrun by an amplified perception of sights, feelings and sounds, Astley, the University of Washington researcher, explained. Imagine wearing a scratchy wool sweater all day in a room full of flashing lights and pounding music, she said; you'd be irritable too.

In Jacob's case, he is easily startled. His mother has learned she must ask permission before hugging him.

After Jacob's diagnosis, the Case family moved to rural Utah, where new homes meet the craggy Wasatch Mountains. The boy's stepfather, Jared, splits his time between there and Alaska's North Slope, where he works as a directional driller.

The doctors they consulted in Utah seemed to know little about fetal alcohol syndrome, Jared Case said. He and Heidi have had trouble finding a suitable child psychiatrist or occupational therapist there. Despite a revolving cocktail of medications, Jacob still rages every day.

"The hardest thing is just knowing that it won't ever go away," Heidi said. "It's not a mental illness. It's not something that can be fixed. It's brain damage."

The Cases have thought of having Jacob carry a special card explaining his disability to onlookers who notice his constant movement and whirling outbursts.

"He's not a bad kid," the card might say, "this is not his fault."



Astley

ALCOHOL
& me
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Heidi
and
Jacob Case



MARC LESTER / Anchorage Daily News

Lounging by the pool on a cruise along the Mexican Riviera, sipping rum and Coke, in 2004, Heidi Case didn't know she was pregnant. Like nearly half of all pregnancies in the U.S., hers was unplanned. It wasn't until her son, Jacob, was 7 years old that she realized her drinking had damaged his brain.

Heidi says she was a binge drinker for only a short time of her life. In this video, she shares her experience in the hope that more women will understand the risks of drinking when they could be pregnant. Heidi says telling the story also helps her.

"I've had a lot of time to process. And the hardest thing is just knowing that it won't ever go away. It's not something that can be fixed."

See next page

Heidi gives Jacob a good-night hug. “For me, obviously, emotionally it’s still really hard,” she says of Jacob’s diagnosis. “And the way that I deal with it is just making sure he lives the best life that he possibly could live.”



Jared Case, at center, talks with his wife and five of their six children in their Utah home. From left, they are Olivia, 6; Heidi, mom; Jared; Alissa, 17; Emily, 15; Haley, 13, and Jacob, 9. Not pictured is Raymond, 12.

Nine-year-old Jacob climbs on the counter to the microwave.



Heidi says she has been having migraine headaches. In addition to Jacob’s FASD, the Cases also have a daughter with autism and another with Asperger’s Syndrome. Her husband, Jared, is gone more than half the time as a driller on the North Slope.



Photos by **MARC LESTER** / Anchorage Daily News

ve oven to heat hot dogs before bedtime. His parents say feeding Jacob is hard because of his pickiness and the erratic times he's hungry.



an half the time, working



During a game of air hockey in the basement family room, Jacob yells, "Shut up! Shut up! Shut up!" at his mother and siblings. Heidi says Jacob's "rages," which often include swearing and throwing things, are an almost-daily occurrence.



Jacob has a playful moment with his father, Jared. Jared, who is not Jacob's biological father, says he has tried for years to try to find appropriate care for Jacob.

‘Rose
are red.
Violits
are blue.
You’re
the best
Mommy
that I ever
new!!’

2. ELAINE, AGE 10

Ten-year-old Elaine crashed into her mother’s arms at the end of the school day. They hugged for a full 15 seconds before walking to the elementary parking lot, pitted ice cracking beneath their boots.

“I can’t believe you’re not wearing a coat,” Jamie Gagnon said.

“I’m a polar bear,” Elaine replied, “I’m never cold.”

Gagnon opened the car door. The dry smell of cigarettes — her last remaining vice, though never with her daughter in the car, she said — vanished in a blast of winter air. Elaine talked excitedly about the stories she is writing.

Once home, Elaine made a beeline for her room, eager to show off the Littlest Pet Shop dolls her mother bought at Value Village.

Elaine loves the toys. She cries when she loses at Sorry or Go Fish, Gagnon said. At the park, she plays by herself. Though she has a few close friends, other girls her age rarely come for sleepovers.

As mother and daughter sat cross-legged on the carpet, Elaine pulled toys from a Ziplock bag. She arranged bobblehead animals in a circle — a menagerie of bulldogs, turtles and toucans.

“I call this one Justin Beaver,” she joked.

As her daughter grew older, Gagnon said, she noticed that Elaine seemed to have the mind of a younger child.



Photos by MARC LESTER / Anchorage Daily News

Jamie Gagnon's daughter, Elaine, was diagnosed with an FASD in 2012. She also has an attention-deficit disorder, but is studious and artistic.

‘WHAT SHOULD I DO IF I THINK I OR MY CHILD MAY SUFFER FROM AN FASD?’

If you recognize the symptoms of FASD in your family and want to know more about the disability, including how to get a diagnosis, a good place to start is by talking with your family doctor or pediatrician.

- Adults curious about a diagnosis might call the nearest diagnostic team. In Anchorage, that’s Assets Inc., (907) 279-6617. A list of other regional teams is online at <http://1.usa.gov/1dTLx0o>.
- Stone Soup Group, a statewide nonprofit that helps families caring for children with special needs, provides basic information on fetal alcohol spectrum disorders and other disabilities, and can be reached at (907) 561-3701.
- General, easy-to-understand information for families can also be found online at nofas.org.

Now five years sober, Gagnon drank heavily during her pregnancy with Elaine. She bought rum by the gallon for much of the first two trimesters.

She lost custody of Elaine (her middle name) while still drinking. When her daughter came home, family members told her Elaine might never be able to live on her own. Gagnon sought a diagnosis two years ago in hopes of learning more about her daughter’s condition.

“I wanted to know how to help her. I did this (to her). I better fix it, to the best of my knowledge,” she said.

The diagnostic team concluded that Elaine was born with an FASD.

“Those caring for and working with (Elaine) need to keep in mind that her behaviors are not willful. She ‘can’t, not won’t,” the team wrote.

Elaine is also athletic, healthy and studious. As with many children with a fetal alcohol spectrum disorder, she struggles with math. She also fears arguments and is overly generous.

Children with FAS or FASD sometimes display “dysmaturity,” meaning their emotional ages are much younger than their actual ages.

“They want a friend and they want to please. And they are sweet,” said Marilyn Pierce-Bulger, a nurse practitioner and member of the Anchorage diagnostic team. “That then makes them vulnerable to individuals who want to take advantage of them.”

Elaine has been a kind-hearted companion, Gagnon said, not just an easy baby but an easygoing kid.

The trophies of a busy child’s life paper the fridge in the family’s South Anchorage apartment: a perfect



Pierce-Bulger

attendance award; an “A” spelling test (Elaine has an “individualized education plan” for math at school but ranks at the top of the class for reading, her mother said); and watercolor paintings of a yellow sun and a field of grass, with a poem written in careful script: “Rose are red. Violits are blue. You’re the best Mommy that I ever new!!”

Gagnon waited until Elaine left the room to discuss her drinking and her daughter’s diagnosis with a reporter. “She’s so smart. Smarter than a whip. It’s hard to talk around her because she catches on way too quick.”

The diagnostic team might see subtle hints of FASD in Elaine’s face, but her classmates see a pretty girl in a pony tail.

Gagnon had never told Elaine about her disability. “I don’t know what I’m going to say,” she said. “Hopefully she won’t hate me.”

Later that night, she said, she decided to talk to Elaine for the first time about fetal alcohol syndrome and her drinking.

“I could have died!” was Elaine’s first reply.

Should they share their story with the world, Gagnon asked Elaine, as she recounted later. She wanted people to learn from her mistake, but she didn’t like the idea of her precious, complicated daughter — a kind girl who writes ghost stories about haunted bathrooms and gets her feelings hurt playing board games — reduced to a label.

“I asked her permission if we could (tell this story) to help someone,” she said. Elaine agreed, her mother said. “She doesn’t want anyone to feel the way I felt back then.”

3. ELIJAH, AGE 8

The boys tell different stories about how Jerriick, 10, fell from a third-story bedroom last July.

Jerrick said his younger brother, 8-year-old Elijah, pushed him. Elijah said Jerrick thought he had super powers and was playing in the window.

He tried to stop Jerrick from falling by throwing him a blanket to hang on to, Elijah said, but the older boy plummeted to the parking lot below.

The fall fractured Jerrick’s pelvis and ankle. He wore a back brace for an injured spine for three months.

Jerrick’s left foot still bends inward when he runs. The only sign of Elijah in the family’s small Government Hill apartment now are photos and artwork on the walls. Elijah appears as an auburn-haired boy with a round face and a toothy, nervous smile.

“He looks like every other kid in class,” said his mother, Susan Essary, 32.

Tacked above the couch was one of Elijah’s paintings, a shapeless swirl of purple and green, like an angry bruise.

“That’s a snowman,” Essary said. Elijah’s signature trails off one corner of the page. Each letter is backward, as if written in a mirror.

See next page



Gagnon prepares Elaine to leave their apartment to play.



Gagnon says she hopes people can learn from her mistake of drinking while pregnant. “If we could help someone,” she says, “it’s worth it.”



Gagnon says she struggled with alcoholism while pregnant. She sought an FASD diagnosis in 2012 to help her care for her daughter. “I did this. I better fix it, to the best of my knowledge,” she says.

The alcohol his mother drank while pregnant isn’t Elijah’s only problem. An older brother died at eight months of age from a head injury that happened while in the care of his father.

The couple later divorced. Essary moved to Alaska and remarried.

By the time Elijah entered day care, his mother saw troubling signs. He was aggressive with other children. When he spoke, the words spilled out in a cascade, making him harder to understand than others his age.

In elementary school, Elijah’s backward handwriting alerted teachers to the possibility of a learning disability. Writing that trails off a page can be a symptom of pre-natal brain damage to the same nerves responsible for a child’s sense of touch, movement and ability to organize.

Elijah’s teachers sat Essary down. Had he ever been tested for fetal alcohol syndrome, they asked.

“What’s that?” Essary replied.

Growing up in Colorado, Essary saw the U.S. Surgeon General’s warnings on liquor bottles but she heard little about the dangers of drinking while pregnant. Even as she learned about FASD, Essary assured herself her son didn’t have the disability. He didn’t look like the pictures the doctors showed her, the kids with a flat, thin upper lip and closely spaced, almond eyes.

Before her divorce, the boys saw domestic violence at home, Essary said. She assumed then — and now — that’s where some of Elijah’s anger came from.

One day when he was 7 years old, Elijah was told he couldn’t play video games. He ran out of the house and started punching a car window. Sometimes he choked the cat.

Astley, the University of Washington expert, said FASD doesn’t necessarily mean someone will be violent or aggressive. In fact, the opposite could be the case. Each child is its own mix of disabling effects. Where it occurs, violent behavior might spring from environmental circumstances or a mental illness unrelated to alcohol.

“Alcohol tends to have it greatest adverse impact on more complex cognitive skills like executive function, higher order language skills, abstract thinking,” she said.

In Essary’s cabinet she keeps the paperwork from Anchorage’s FAS diagnostic team. It says Elijah has a form of FASD, with an IQ in the 70s. She drank enough before she knew she was pregnant to cause permanent brain damage and likely behavior problems, but not enough in the third week of pregnancy to create the trio of facial features necessary for a full FAS diagnosis.

Elijah had other problems with movement and coordination, the experts found. For example, he catches a ball by letting it hit his chest and clutching it, the way a much younger child would.

“He’s young. I can let the school know he has a form

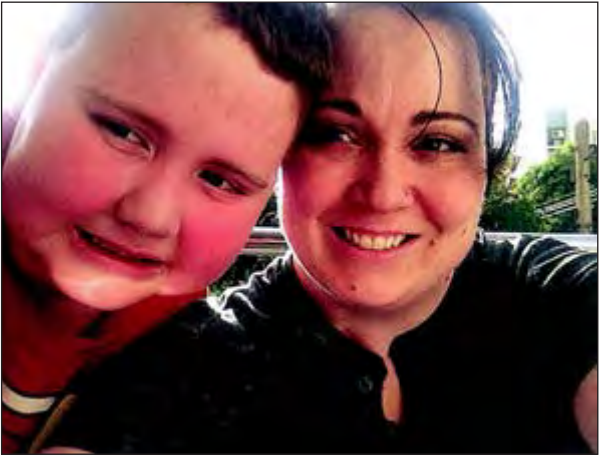


Photo courtesy SUSAN ESSARY

Susan Essary and her son, Elijah.

of FASD,” Essary said. “We can get him the help he needs with special education.”

Only a fraction of children diagnosed with fetal alcohol syndrome live with their biological parents. Some, like Jacob, spend time in treatment. Others grow up in foster homes, or with extended family or adoptive parents, who face formidable parenting demands.

An FASD child might lie when it would be easy to tell the truth. He or she might manage time poorly, chatter incessantly, be quick to anger or become resentful. Like children with attention deficit disorders — and many children exposed to alcohol in the womb are also diagnosed with ADHD — they often act impulsively, without considering possible consequences.

As they grow into adults, the brain damage may make it harder to maintain relationships, raise children of their own or keep a job.

Some FASD adults require state-paid public guardians to manage their money, pay their bills and help them shop. Fewer than one in 10 adults with a full fetal alcohol syndrome diagnosis can live without assistance, according to University of Washington researchers.

For now, Elijah lives 1,800 miles from downtown Anchorage, in Butte, Mont., in a 68-bed treatment center for children with serious behavioral, emotional or psychiatric disorders. He still has bouts of anger that doctors try to tame with medication, Essary said.

“They told me that he would basically need help for the rest of his life,” she said.

Essary visited Elijah in Montana last week, taking him swimming in a hotel pool and shopping for clothes. He has grown more than 3 inches since she last saw him, in the fall.

See next page

What separates FASD from FAS?

FASD stands for fetal alcohol spectrum disorders, an umbrella term that refers to a variety of disabilities and birth defects caused by a mother’s alcohol consumption while pregnant.

FAS stands for fetal alcohol syndrome, a specific medical condition that includes a trio of distinct facial features, undersized height and weight, and damage to the central nervous system. It is considered the most severe of the fetal alcohol spectrum disorders.

4. SERENITY, AGE 6

For 16 months, Serenity spent weeknights at the home of a therapeutic foster family. On her first night home for good with her mother, Helen Benson, a “welcome home” cake greeted her. The 6-year-old beamed.

Benson heated a pot of stew and picked out all the peas while Serenity drew pictures in the living room of their Muldoon apartment. She quietly colored her hands green with a marker.

Serenity’s mood darkened after dessert. She snapped at her sister and at the family’s Australian shepherd, Sasha. When her mom tried to convince her to take her pills, she turned her back.

By bedtime, Serenity was ready for a fight. She planned to sleep on the couch, she informed her mom. She planned to stay up all night and would not be going to school the next morning.

Benson calmly disagreed. She tried to lift her daughter, but Serenity stiffened her body to make it harder. On the way to the bedroom, she held on to each door jamb and kicked Benson in the shin.

As soon as she was put to bed, Serenity raced back to the couch.

“Why are you acting like this?” Benson asked.

“Because you’re stupid,” Serenity said.

On the living room wall, a handwritten sign reminded Helen of appropriate responses to her daughter. “(I) Love you too much to argue” was at the top.

Deflated, Benson stepped out onto the porch, drawing deep breaths in the falling snow. “I wish I could say that, every time I deal with it, it gets a little easier . . . But every single time I have to deal with these episodes, it wipes me out.”

Inside, Serenity had surrendered the battle for the couch and vanished to the apartment’s only bedroom. Within 15 minutes, she was asleep on top of the covers, the green marker in her mouth.

Helen said she remained optimistic about having her daughter home. Tomorrow might not be anything like this, she said.



MARC LESTER / Anchorage Daily News

Serenity withdraws from her mother and sister one day last December. Despite the challenges, Helen says she’s encouraged by how things have gone since Serenity moved back home. “We’ve had some bad patches, but that’s what they are, they’re patches,” Benson says. “They’re not bad days. They’re not bad weeks. They’re bad moments.”

The little girl who was such an easy baby and quiet toddler began launching into hours-long rages by the time she was 3. The low point came in 2012 when Serenity purposefully slammed a heavy sliding door on the hand of her year-old sister.

“She became dangerous to not just me and herself, but also to her sister,” Benson said. “At that point, I knew, ‘OK, this isn’t going to get better.’ ”

Serenity spent three stints at North Star Behavioral Health, an Anchorage treatment center. The staff there recommended she be tested for an FASD. At times, she lived with specially trained foster parents on weekdays as an alternative to full-time residential treatment.

Meeting with the various experts who would determine whether she had fetal alcohol syndrome — a psychologist, a medical professional, a speech therapist and an occupational therapist — took months.

“I didn’t know whether I wanted it or not,” Benson said of the testing. “On one hand, it gives answers. On the other hand, it puts the full responsibility on my shoulders. I have to say, ‘I did this to my child.’ ”

“The key for me was just getting past my own guilt and focusing on what she needs,” Benson said.

Now 7 years old, Serenity has a high IQ, a good sense of humor and partial fetal alcohol syndrome, experts found. Emotionally, her behavior is closer to her toddler sister Lexie than her peers at school, Benson said.

Earlier this month Serenity became upset about a kid’s meal toy at McDonald’s. She had to be carried to the car by Benson and the family’s case manager at Denali Family Services, Benson said. Throwing anything

she could grab from her car seat, Serenity tried to kick her mother. She hit the case worker instead, putting the woman’s arm in a sling for four days.

With the right medication and people around her who understand why she can’t always control her impulses, Benson thinks her daughter will be able to live on her own as an adult.

Though her medical diagnosis says she has the hallmark facial features of FAS, she looks to the world like any other first-grader. Lexi, now 2, mistakes pictures of Shirley Temple in DVD movies for her curly-haired big sister.

Since her diagnosis, Serenity also takes two daily medications — one to reduce hyperactivity and another for mood swings.

“They don’t make me playful and they make me fall asleep,” Serenity protested on a recent day.

Benson can remember just three meltdowns in the past three weeks.

“I can handle that,” she said. “It used to be three meltdowns a day.”

The family’s Ford Explorer, which was donated by a local church, idled outside for the drive to school. As Serenity tapped on an iPad, Benson noticed her daughter’s knitted brow.

“I’m not talking bad about you, hon,” she said.

Serenity made no reply, frowning at the screen.

Benson tries not to judge herself too harshly.

“My own mother was a die-hard drunk,” she said.

Email khopkins@adn.com and mlester@adn.com

Benson began her recovery from alcohol and drug addiction while pregnant with Serenity. In 2012, Serenity was diagnosed with partial fetal alcohol syndrome. “She is the way she is because of me, yes,” Benson says. “I did what I did. I can’t change that. But what I can do is fight like hell to get her what she needs.”





Six-year-old Serenity sits at home. Serenity's mother, Helen, began recovering from drug and alcohol addiction while pregnant and staying in a domestic violence shelter in South Carolina.

Benson tries to carry Serenity to bed. Serenity's mood changed quickly, Benson says, which led to more than an hour of defiant behavior. "I wish I could say that, every time I deal with it, it gets a little easier ..." Benson says. "But every single time I have to deal with one of these episodes it wipes me out. It's really exhausting."



MARC LESTER / Anchorage Daily News

ALCOHOL & me

Helen
and Serenity
Benson



MARC LESTER / Anchorage Daily News

Helen Benson changed her life while staying at a shelter for abused women. Pregnant with her daughter, Serenity, she turned away from a lifestyle of alcohol and drugs that she was desperate to overcome.

Now sober for seven years, other challenges remain. In 2012, Serenity was diagnosed with partial fetal alcohol syndrome. For Helen it helps explain her daughter's behavior, which she first noticed shortly after Serenity was born.

Helen says she understands her actions caused her daughter's permanent condition. In this video, she shares her experience and explains why getting a proper diagnosis was crucial to her new mission.

"She is the way she is because of me, yes. Is there guilt? Yeah, there is. I did what I did. I can't change that. But what I can do is fight like hell to get her what she needs."



Benson surprises Serenity with a "Welcome Home" cake. Serenity had been in a therapeutic foster home for about 17 months as they both learned to better handle Serenity's behavior issues, Benson says.

It takes courage to talk about your own drinking while pregnant. The mothers in these stories did so in the hope of preventing more babies from being born with a fetal alcohol spectrum disorder. The Daily News is grateful to Helen, Susan, Jamie and Heidi for sharing their stories.

*Patrick Dougherty,
Daily News editor*

About State of Intoxication

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We want to hear your ideas, your stories

If you would like to tell your own story, or have ideas for ways that Alaska can prevent FASD or help people with the disability, please email us at alcohol@adn.com. Join the conversation on Facebook or Twitter (use the hashtag #FASD).