FASD fact #1:

“FASD” = fetal alcohol spectrum disorder.

“FASD” is not a diagnosis, but an umbrella term that includes a variety of medical diagnoses, including FAS (fetal alcohol syndrome), pFAS (partial fetal alcohol syndrome), ARND (alcohol related neurodevelopmental disorder), static encephalopathy, and a neurodevelopmental diagnosis: ND-PAE (Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure), which is in the DSM V, as well as other diagnostic terms.

All of the FASDs share one symptom in common: brain changes caused by alcohol exposure in utero.

Most of the time, the only symptom of FASDs are behavioral changes.

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2-5% of babies born in the United States have an FASD.

That means 2-5% of the people – children and adults – have an FASD.

In other words, between 1 in every 50 and 1 in every 20 people are living with an FASD.

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Source: May, et. al 2009: https://pdfs.semanticscholar.org/9574/f10d44c51adde7a1abfc01dbf03a09f11c78.pdf
FASD Fact #3
Even though the number of people WITH an FASD is between 1 in 50 and 1 in 20, only 1 in 1000 are diagnosed. This means that almost 99% of people with FASDs are not correctly diagnosed.
And yes, diagnosis matters. Research tells us it’s a major factor in preventing poor outcomes for people with an FASD.

(diagnostic/prevalence rates can be found at cdc.gov; other sources can be found on the 50facts page on our website, fafasd.org)
Alcohol exposure in utero impacts the brain on a structural, functional, and cellular level. Behavioral differences are often the only symptoms. **FASD is an invisible, physical disability.** The brain is part of the body, isn’t it?

Since FASD is a physical disability, we must provide accommodations and environmental change, just as we do for all other physical disabilities.

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Behavioral differences associated with FASD can be divided into 2 types:

1. **Primary characteristics**, which are associated with brain differences.
   - Include: memory, processing, and executive functioning differences, liability in mood, increased fight or flight, difficulty with abstraction, developmental dysmaturity, sensory differences.

2. **Secondary characteristics**, which are the result of unmet needs and result from judgement and misinterpretation of behavior over time.
   - Include: aggression, depression, anxiety, and isolation.

3. **Tertiary problems**, like homelessness, incarceration, substance abuse, institutionalization, and lack of employment happen when secondary characteristics are left un-helped.

Source: Streissguth et al, 1996)
Diagnosis and understanding of the disorder is key in avoiding poor outcomes for individuals with FASDs.

- Diagnosis on the FASD spectrum is important, and understanding how fetal alcohol exposure impacts the brain, and therefore behavior, is equally important.

- Diagnosis and understanding leads to more functional families who are better able to care for their loved ones with FASDs.

(Petrenko et al, 2016)

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Accommodating a person’s brain differences through environmental change – like lowering stimulation, like matching expectations to ability, like providing tools to aid memory - is JUST LIKE accommodating a mobility-impaired person by providing a wheelchair and ramps.

FASD is an invisible disability. Just because you can’t see it doesn’t mean it doesn’t exist. Behavioral differences are often the ONLY symptoms.

FASD Fact #7:

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One primary brain difference of FASD is slower processing speed.

Behaviorally, this might look like a person responding slowly to requests. People with FASD might react, and refuse a request, then think about it and comply. They might become overwhelmed with lots of talking or noise. They might say “huh?” or “what?” a lot.

This can look like ignoring, daydreaming, or opposition, but when given adequate time and understanding, can be seen as the brain needing more time to process requests and directions.

Strategies around slow processing: GIVE TIME. Use fewer words. Understand that this is NOT ignoring or opposition.

Fact #8
Fact #9
One of the primary characteristics of FASD is difficulty with executive functioning.

This means that organization, planning, transitioning, goal-setting, self-modulation and self-inhibition can be challenging!

An important way to help a person who has difficulty executive functioning is to recognize that this is a brain-based behavior. It’s not laziness, or messiness, or procrastination, or immaturity. Provide help with organization, or setting a goal and planning to reach that goal, or getting started, or sticking with it, or working through problems! Seek out technology that can assist with these tasks. Use the person’s strengths (like understanding a visual, or sticking to a schedule) to find solutions! Set up the environment for success.
Fact #10: Sensory differences are a primary characteristic of FASD. Sensory seeking and sensory avoiding behaviors are common. Examples of this are “picky” behavior around food, insensitivity to pain, oversensitivity to noise, or ramping up in response to sensory overload with difficulty calming back down.

Strategies to help: recognize that these sensory differences are REAL. Change the environment and environmental demands to prevent problems!
Up days and down days are common for people with an FASD.

- Alcohol exposure in utero can impact memory, processing speed, stamina, and cause other global cognitive problems. For a person with an FASD, being able to do a task one day (or one hour) and struggling with that task the next is normal.

- Some basic strategies to help include: understanding that this behavior is not purposeful; providing reminders, allowing for more time, giving support, and reteaching.
Fact # 12: Perseveration is a common behavior for people with FASDs.

Perseveration is repetitive and continuous behavior, such as repeating the same word or phrase, or the inability to stop thinking about a topic. It’s as if the brain is stuck in a loop.

Perseveration is very difficult to stop, frustrating to live, and strategies are individual to the individual. Some people report success with distraction, some suggest talking out the issue, and some say that setting a clear boundary around the subject works best.
When a person has a disability, we change their environment to help them succeed. This is true for people with FASDs as well.

“Environment” can be sensory: what you can see, smell, touch, hear, and taste.

“Environment” can be more abstract, such as expectations, systems, traditions, values, and culture.

Instead of making the person with an FASD fit the environment, we need to change the environment to fit the person with an FASD.
Confabulation is when the brain fills in gaps of understanding or of memory.

To the outsider, it sounds like lying, fabrication, or fantasy.

To the person who is confabulating, it seems real.

Confabulation can lead to suggestibility, misunderstandings, false confessions, and victimization.

Confabulation is NOT purposeful deception.

Confabulation is common for many people who have an FASD.

Strategies to help with confabulation: stop blaming, accusing, and shift your understanding of the false information from lying to a brain-based symptom.

A positive, trusting relationship can help when the person who is confabulating needs support. Educate the person with an FASD about confabulation as well as his/her support system.
One factor that leads to more positive outcomes for people with FASDs is qualification for developmental disability supports. We’ve known this for 20+ years (Streissguth et al, 1996)

As of 2018, not a single state in the US uses a diagnosis on the FASD spectrum as a qualifier for developmental disability supports. In many states this is not the case for certain other developmental disabilities, like autism.

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FASD Fact #16

A primary characteristic of FASD is developmental dysmaturity. Children and adolescents with FASD often experience a significant developmental difference from their same-aged peers.

Developmental dysmaturity looks like immaturity. It can look like “acting like a baby.” But it is really a brain-based symptom of FASD. It can impact social situations, communication, and life skills. It may mean a prolonged adolescence, or the need to parent and/or support the person well into legal adulthood and beyond.

Strategies include ACCEPTANCE and UNDERSTANDING. Give the person with an FASD expectations that match their developmental age! Adjust the environment to match what they can do!
FASD Fact #17: Impulsivity is common for people with FASDs

Impulsivity is a common symptom of FASD. Impulsivity can impact all facets of a person’s life, from ability to communicate, to life skills, to social-emotional situations, and to safety.

Impulsive actions occur without forethought. They are not on purpose.

Strategies to help people who have problems with impulsivity are to supervise, provide support, provide non-judgmental reminders, and manage the environment to prevent problems.
FASD Fact #18

Difficulty with memory, particularly short term memory, is a primary characteristic of FASD.

Memory issues are directly related to the documented brain differences that occur during alcohol exposure on the developing brain.

It's not a sign of people not trying, or not caring. It's a sign that their brains work differently.

Strategies to accommodate folks who struggle with memory include reminders and mnemonic devices, including apps and other technology to provide reminders. Visual cues, or using other methods that work with a person’s strengths as well as providing structure and predictability, can also help a person know what to do if they struggle with retention.

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FASD Fact #19

People with FASDs and their families need FASD-informed professionals to help them.

Most professionals (doctors, therapists, teachers, psychologists, social workers, and other “experts” are not FASD informed.

“Participants emphasized the pervasive lack of knowledge of FASD throughout multiple systems. This lack of knowledge contributes to multi-system barriers including delayed diagnosis, unavailability of services, and difficulty qualifying for, implementing, and maintaining services.”


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An FASD informed professional approach “recognizes that to achieve positive outcomes, it is the system, program, and/or service providers who need to make modifications rather than the person with FASD.”

This includes programming and support that

a) is aware and informed about FASD,

b) makes person-centered accommodations, and

c) is strengths-based.

FASD Fact #21

Difficulty with abstract thinking is a primary characteristic of FASD.

Abstract concepts, like time, money, inferences, and idioms, can be very difficult for people with FASDs to understand.

We can help people with FASDs with abstractions by being concrete in our explanations and in our language. We can recognize that tasks like making decisions, or managing time, or managing money, can be difficult and offer assistance, structure and strengths-based solutions!
FASD Fact #22

Visual/Spatial differences are a primary characteristic of FASD. This can look like “clumsiness” or disregarding personal boundaries, but reflects difficulty perceiving one's own body in space. Understanding left/right differences are common. Handwriting that is large or doesn’t follow a straight line also can be a sign of visual/spatial differences.

Strategies include recognition that this is a brain-based difference. **It’s not carelessness, laziness, or rudeness.** Gentle reminders, structure, and work-arounds that could include technological assists are appropriate. Provide a calm visual environment to prevent overwhelm.
FASD Fact #23

The life expectancy of people with FASDs is 34 years old*. The bulk of these early deaths are NOT due to congenital health problems. The bulk are due to suicide, overdose, and accident. These are the result of poor fit, lack of services and support, and uneducated providers.

We MUST change this statistic.

Life Expectancy of People with Fetal Alcohol Syndrome.
Thanh NX, Jonsson E.
A primary characteristic of FASD is difficulty with emotional regulation. This can look like “overreaction,” difficulty calming down, or hair-trigger explosions. It can express itself in rages or low mood or irritability.

Strategies to help with mood liability include not taking it personally, teaching self-calming strategies, giving breaks, and helping the person learn the physical signs of rages or explosive reactions so they will know when to use their strategies. Calm environments and matching expectations to ability are also key.

When these strategies help, don’t assume the person is “healed.” Assume the need to keep these accommodations in place.
Overeating, not feeling satiated, not feeling hunger signals, under-eating, the need to snack, and cravings for sugar and other simple carbohydrates are all common for people with FASDs.

Add to that any past experience with food insecurity and food/eating/nutrition can be a point of difficulty for people with FASDs and caregivers.

Strategies around issues with food include: accept that this is a REAL consequence of alcohol exposure in utero. Some people may benefit from schedules and structure around eating, others may benefit by having plentiful healthy snack food available all the time, and others may need to be taught what their body signals are telling them. Avoid making food/mealtime a battle.

Caregivers may have to let go of preconceived values about mealtimes and communal eating.

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FASD Fact #26: To help people with FASD, we must focus on strengths! We acknowledge difficulty and provide supports, but strengths are how we all move forward.

These are just some of the strengths attributed to their loved ones by the families of the Shifting the Paradigm group on Facebook.

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FASD Fact #27: People with FASD are much more than their differences! They are individuals with many strengths!

- Outgoing
- Sociable
- Strong
- Determined
- Doesn’t quit
- Mechanically inclined
- A wonderful child!
- Great builder
- Loves animals
- Empathetic
- Passionate
- Focused
- Funny
- Creative
- Gentle
- Goofy
- Hardworking
- Sensitive
- Fun
- Bright
- Athletic
- Skilled
- Musical
- Artistic
- Goal-setter

These are just some of the strengths attributed to their loved ones by the families of the Shifting the Paradigm group on Facebook.

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Children with FASD grow up to be adults with FASD, but FASD is not the only thing that defines them!

These are just some of the futures reported by the families connected with FAFASD!
FASD Fact #29
Families impacted by FASD recognize amazing qualities in their loved ones.

- Empathetic
- Helping
- Observant
- Navigator
- Amazing photographer
- Athlete
- Loyal
- Great sense of self-worth
- Hilarious
- Resilient
- Resourceful
- Passionate
- Joyful
- Forgiving
- Insightful
- Musical
- Curious
- Creative
- Visual
- Technical
- Great builder
- Smart
- Good with children
- Good with animals
- Great friend
- Loves his family
- Good manners
- Determined
- Perseveres
FASD Fact #30
Wide-spread, systemic barriers prevent understanding and support for people living with FASDs.

System Level Barriers that lead to difficulty understanding FASDs:

- Lack of knowledge about FASD and understanding of how it presents
- Inadequate training of providers
- Inadequate community education
- Lack of diagnostic capacity
- Lack of intervention services

These all lead to secondary characteristics.

FASD Fact #31:
One barrier to diagnosis, supports, and services to people with FASDs is a diagnostic process that relies on identification of specific facial features.

- Approximately 1% of people who have an FASD are diagnosed. We know that diagnosis is a key to preventing poor outcomes (see fasdfact #6).
- Of those, a small percentage have specific facial features associated with a diagnosis of FULL FAS*.
- Facial features are one of the 4 criteria for diagnosis for most clinics and diagnostic facilities in the US. Most doctors and other specialists ONLY know this symptom of FASD**.
- This results in a huge percentage of mis- and missed diagnoses.

** (Arnold K et al, 2013)
Caregivers of people with FASDs experience high levels of stress.

Caregiver stress can lead to a lower ability to cope with the needs of loved ones, disrupted work, issues with health, and burnout.

Caregiver stress is directly related with a lack of educated and informed systems and supports.

Caregiver stress and burnout creates a BARRIER to support and understanding of people with FASDs and contributes to secondary characteristics.

Shame and stigma around alcohol use during pregnancy is a barrier to care for those living with FASDs.

Prevention-focused messages perpetuate this stigma.

Stigma towards mothers whose children were exposed to alcohol in utero extends to their children with FASDs.

Stigma guides policy decisions, funding, diagnosis, identification, and support in a negative way – for the mothers of people with FASDs AND THEIR CHILDREN.

FASD Fact #33:

Myth: “nothing works” for people with FASDs.

Reality: we cannot cure the brain differences caused by FASDs, but understanding FASD and its impact on the brain, recognizing the associated behavioral symptoms, and responding with accommodations and environmental change creates positive change for people with FASDs and their families!
FASD is a lifelong neurobehavioral and neurodevelopmental disability. Behavioral differences are SYMPTOMS of brain differences. As such, it should qualify a person for the same supports and services that other people with developmental disabilities get: supported housing, supported employment, supported living, and financial support.

FASD Fact #35: The myth that FASD is “just” a behavioral problem prevents people with FASD from receiving proper care.
Everyone involved with the person with FASD needs to be FASD informed.

Everyone

This means parents, family, caregivers, support workers, doctors, therapists, teachers, school administrators, employers, social services providers, police, judges and anyone else who touches the person’s life.

FASD Fact #36:

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FASD Fact #37: Myths about the women who give birth to children with FASD prevent awareness, proper diagnosis, and support for people with FASDS.

If we believe that FASD only happens to “others” – like poor people or addicts – we will not see it as the MAJOR PUBLIC HEALTH crisis that it is.

Women who give birth to children with FASD are in every socio-economic class and from every ethnicity. Some are addicts, but some are not.

Half of all pregnancies are unplanned and half of all child-bearing women drink alcohol.

DO THE MATH.

FASD impacts everyone.

Many behavioral symptoms of FASD are due to a combination of differing brain functions.

For example, explosive rages could be:

- Sensory overload
- Overactive limbic response (fight or flight)
- Difficulty communicating
- “Age” appropriate developmental differences (meaning a reaction appropriate for developmental age, vs. chronological)
- FRUSTRATION due to being misunderstood or punished for behaviors directly related to a person’s disability
- Stress response due to inappropriate consequences over time
- Low blood sugar, mitigated by sugar cravings and a need for more frequent meals/higher quality foods

Or any combination of the above (plus many other possibilities)…
We have years of evidence and 20,000+ published studies on the impact of FASD on the brain.

How FASD happens (through alcohol exposure during pregnancy) and what it does (alters the structure and function of the brain, down to the cellular level) and what it looks like (common behavioral symptoms) are FACTS, all well documented in scientific literature.

FASD Fact #39:
How FASD happens and what it does to the brain is well documented.
(And yet, many professionals don’t understand it, can’t diagnose, or even deny that it exists…)

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### FASD Fact #40:
The brains of people with FASDs are less “plastic” than the brains of neurotypical people.

| Neuroplasticity is the ability of the brain to change and heal in response to stimuli. |
| People with FASD have brains that are different on a cellular, developmental, chemical, structural, and functional level. Their brains have less capacity for neuroplasticity. |
| Therapies and intervention that rely on neuroplasticity to improve brain function are less effective for people with FASDs. |
| People with FASDs CAN learn! But the focus needs to be growing their strengths vs. trying to “fix” their disability. |

Source: Kolb et al, 2011; 2015
FASD Fact #41
FASD is not a mental illness.

- FASD is a neurodevelopmental and neurobehavioral disorder.
- It is not a mental illness.
- Mental illnesses can co-occur for people with FASDs, but not all people with FASDs have mental illnesses.
- Secondary characteristics of depression, anxiety, isolation, aggression, and other reactions to unmet needs are common for people with FASDs.
- When people with FASDs seek help with mental illnesses or secondary conditions, it’s important that they have access to providers and treatment options that fully understand FASD.

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FASD Fact 42:
Developmental differences, suggestibility, and difficulty predicting consequences put people with FASDs at risk for victimization, scapegoating, and false confessions.

When caregivers and families of people with FASD are burnt out, left with no resources, and exhausted they find it difficult to advocate for their loved ones...or for FASD awareness in general.

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FASD Fact #44

FASD is a spectrum disorder. Timing and amount of alcohol consumption, age and health of the mother, number of previous children, genetics, and other factors all impact the changes in the developing brain when it’s exposed to alcohol.

People with FASDs have certain brain differences in common, but if you’ve met one person with an FASD…you’ve met one person with an FASD!

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FASD Fact #45

Families affected by FASD need change.
People affected by FASD need change.
We need society to shift understanding of behavioral symptoms from “they won’t” to “they can’t.”
It’s a crucial piece of the puzzle for our community.

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When it comes to living with, helping, supporting, loving, and being with a person with an FASD, we must ALWAYS think brain.
If 2-5% of the population has an FASD, that means 6.5 – 16 million people are living with FASD in the USA.

6.5 – 16 million

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There is no known medicine to “cure” FASD.

While doctors and parents often try to treat the symptoms of FASD with pharmaceuticals, and individuals have reported varying degrees of success, parents also report that some medicines intended to help the symptoms of FASD cause their children unexpected side effects.

Alcohol exposure in utero changes the brain on a cellular and neurochemical level.

FACT 1: To change behavior in anticipation of a consequence, positive or negative, the brain needs to be able to curb impulses, inhibit fight or flight responses, remember the “rules,” remember the consequences, predict what will happen, think abstractly, process quickly, generalize between situations…at the very least.

FACT 2. People with FASD have brains that have difficulty curbing impulses, inhibiting fight or flight, remembering rules and consequences, predicting future events, thinking abstractly, difficulty generalizing, and processing quickly.

LOGICAL CONCLUSION: Fact 1 + Fact 2 = consequence based behavioral modification is predictably ineffective, and in fact can end up backfiring, since to the person being punished (or not getting rewards) this method seems arbitrary.
“We are capable and able to do anything with the right support in our lives!”

“Just because I’m disabled doesn’t mean I can’t do stuff!”

“I’m not immature...I have an FASD.”

“It helps when people understand – like, really understand.”

“I’m not trying to misbehave.”

“Please change your vocabulary of “won’t” to “can’t” when you are discussing my condition with anyone.”

“Diagnosis was a relief. I learned I wasn’t the problem...I HAD a problem.”

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