Seeing FASD Differently: Reframing Misperceptions About Behaviors Through an FASD-Informed Perspective

FASD UNITED

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Table of Contents

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Introduction to FASD

What is FASD?

Fetal alcohol spectrum disorders (FASD) are a group of conditions that can occur in a person exposed to alcohol before birth. These neurodevelopmental conditions can affect each person in different ways. People with FASDs can have lifelong effects, including challenges with behavior and learning as well as physical problems.[1] Individuals with FASD also show a wide range of strengths.[2]

FASDs are described as a spectrum because prenatal alcohol exposure affects each person differently. Every individual has a unique combination of strengths, challenges, and support needs, so no two people with FASD have the same experience.

The effects of FASD are lifelong and often become compounded over time.[3] Experiences may change throughout the lifespan[4]—from feeding difficulties in infancy and school concerns in childhood to behavioral and mental health concerns in adolescence and employment, housing, financial, relationship, or legal issues in adulthood.[5] Every person with FASD is impacted differently and has both unique strengths and support needs.[6]

1 in 20 children in the US has an FASD.[7]

Misperceptions & Judgmental Attitudes

People with FASD, their families, and those who consumed alcohol during pregnancy are often subject to harmful misperceptions and judgmental attitudes. This can have negative impacts such as lower self-esteem, difficulties in social interactions, social isolation, reluctance to seek help, and discriminatory attitudes.[8]

Common Misconceptions about Caregivers

PERCEPTION	*FASD-INFORMED REALITY*
Poor parenting	**Caregivers often tailor their parenting strategies to meet the individual's unique needs.**
Overprotective	**Extra supervision may be needed to promote safety, independence, and successful decision-making.**
Overreacting	**Caregivers often recognize triggers, safety concerns, and support needs that may not be apparent to others**

It’s important to remember that parents and caregivers of children with FASD often go to great lengths to support their children through adapting parenting strategies to meet the unique needs of their child.

Strengths & Positive Traits

Seeing FASD differently means moving away from harmful misperceptions and instead focusing on strengths and support.

Individuals with FASD have many strengths and positive qualities. Common strengths observed in individuals with FASD include: being loving, forming strong relationships and connections, being sociable, showing trust, resilience, adapability, and creativity.[9] **Every person with FASD is unique, and their unique strengths deserve to be celebrated.**

Check out our *Language Guide* for suggestions on how to talk about FASD.

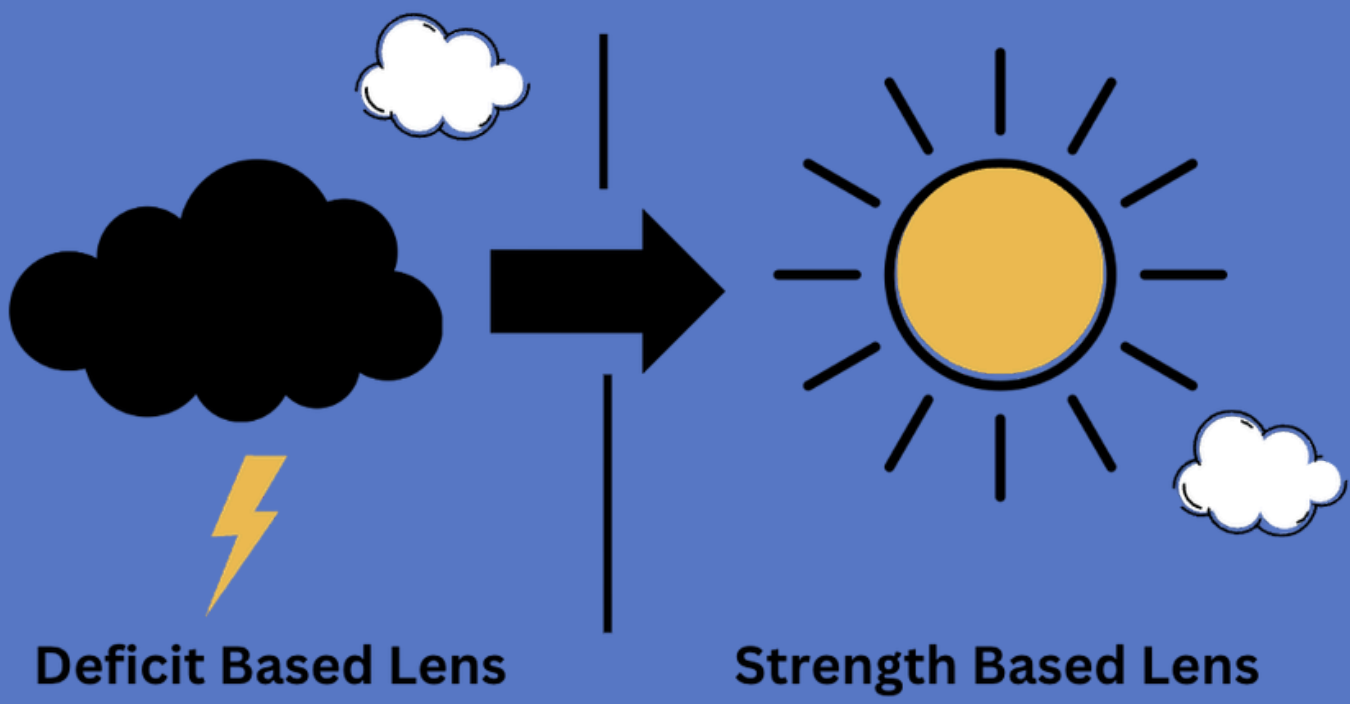
"You are more than a diagnosis or a list of diagnoses. What you live with may shape your needs and your days, but it does not define your worth. You move through life with complexity, finding your own ways to adapt and endure. Your pace may be different, yet your value remains. There is room to accept yourself as you are today, to allow rest, support, meaning, and dignity. You are more than survival—you carry a voice and lived wisdom that matter." - Carl, self-advocate

Researchers have also identified notable positive traits in parents and caregivers of individuals with FASD. They possess significant strengths in their ability to adapt for their families and to respond with patience, understanding, and flexibility to the needs of their children with FASD.[10]

Reframing Behaviors

Behaviors Aren't Always Intentional

Many behaviors associated with FASD are often misunderstood as intentional defiance or misbehavior. Instead, it is recommended to **consider an FASD-informed approach that recognizes brain-based differences and focuses on understanding support needs** rather than assuming intentional behavior.



Individuals with FASD can face unique complexities, including difficulties with executive functioning, memory, emotional regulation, and social interactions. **This guide intends to help individuals and their support team navigate common obstacles through an FASD-informed lens, including information, strategies, and resources to enhance overall wellbeing to help individuals and families thrive.**

Time Management

Addressing Time Management

For individuals with FASD, executive functioning difficulties can make it hard to judge how much time is needed for a task, as well as the sequence of steps. This can lead to a pattern of putting things off with the intention of doing them later, yet 'later' may never happen. Not out of avoidance, but because starting a task can be genuinely difficult when executive functioning is affected. Memory challenges can also make it harder to remember important tasks or responsibilities.

Common Misconceptions about Time Management

PERCEPTION	*FASD-INFORMED REALITY*
Difficulty with time management	**Can become fixated on an activity and doesn't notice time passing**
Forgetting appointments or plans	**Concepts of time and/or verbal reminders don't always stick**
Procrastination	**Can be hard to tell when something needs to be done "now" vs. "later"**
Inconsistent time estimation	**Can overestimate or underestimate how long an activity will take**

Strategy: **Set timers and alarms**	Use a timer or alarm which can provide constant reminders as well as allow the passage of time to be easier to track.
Strategy: **Use visual schedules**	Use pictures, icons, or photos to reduce reliance on memory and remember what comes next.
Strategy: **Practice a routine**	Practice steps for an activity during a calm moment to build muscle memory and estimate how long the tasks should take.
Strategy: **Try body doubling**	Sit or work quietly near someone while you complete tasks to help anchor focus.
Strategy: **Use clear, simple instructions**	Practice giving one specific step at a time rather than a long list, as well as avoiding open ended time phrases like "in a little bit."

Check out Dr. Spiller's resource explaining how understanding time doesn't always mean being able to manage it.

Emotional Regulation

Addressing Emotional Regulation

Individuals with FASD often have difficulty with emotional understanding, such as recognizing that multiple emotions can occur at once and identifying emotions in themselves and others. Furthermore, emotional, social and cognitive development may lag behind chronological age which can mean increased vulnerability to peer pressure, exploitation and challenges in relationships.

Common Misconceptions about Emotional Regulation

PERCEPTION	*FASD-INFORMED REALITY*
Immaturity	Emotional, social and cognitive development can lag behind chronological age
Poor impulse control	Hard to think through actions or consider consequences before doing something
Emotional outbursts	Sensory processing differences may lead to feeling overwhelmed and dysregulated
Socially inappropriate behavior	Developmental mismatch in judgment, impulse control, and social understanding

Strategy: **Focus on breathing**	**Take slow, deep breaths which can help calm the body's stress response and reduce feelings of overwhelm.**
Strategy: **Decrease noise and dim lights**	**Limit distractions, reduce background noise, and use softer lighting to support focus and reduce stress.**
Strategy: **Sit quietly nearby**	**Offering calm, nonintrusive support by sitting nearby without expecting social interaction or eye contact.**
Strategy: **Practice empathy**	**Taking time to recognize and/or name emotions can lead to an increase in self-awareness as well as improve communication.**
Strategy: **Use low demand approach**	**Celebrate and verbally praise successes big and small and/or completed steps to reduce anxiety and build confidence.**

Caregivers of individuals with FASD can experience high levels of stress. ***Scan the QR code & try these self-care routines to see what helps you feel more regulated.***

Ownership

Addressing Ownership

FASD is a brain-based disability that can affect impulse control, memory, and executive functioning. These differences can make it hard for a person to pause, think ahead, and manage impulses in the moment. This can lead to taking something that doesn't belong to them. This might happen because they do not fully understand ownership as an abstract concept. Others may understand it but still lack the impulse control needed to stop themselves from taking something they want.

Common Misconceptions about Ownership

PERCEPTION	*FASD-INFORMED REALITY*
Being disrespectful	**May struggle with understanding social cues and communication skills**
Rule-breaking	**May have difficulty remembering rules or when to follow them**
Intentional theft	**Difficulty with impulse control, which can lead to taking items without thinking about effects**
Being dishonest	**Memory differences may affect how events are remembered or recalled**

Strategy: **Discuss boundaries**	**Discuss ownership and difference between wanting, finding, borrowing, and owning.**
Strategy: **Supervise**	**Provide supervision as much as possible, especially in higher risk settings.**
Strategy: **Teach ownership in concrete ways**	**Use visual reminders and simple, consistent rules.**
Strategy: **Be curious**	**Ask questions and seek understanding instead of accusing or correcting.**
Strategy: **Reduce anxiety**	**Anxiety makes impulse control worse. Practice self-care strategies to reduce anxiety.**
Strategy: **Role play**	**Practice returning items, and role-play common situations**

Check out this resource from the FASD Network of Southern California on ownership and impulse control.

Social Skills

Addressing Social Skills

Deficits in executive functioning can make it challenging to navigate impulse control, making it harder to pause, plan and think through the impact of actions and how they may impact others. Individuals can also experience difficulty in understanding concepts such as empathy and sharing, affecting the ability to prioritize others' needs and feelings.

Common Misconceptions about Social Skills ↘

PERCEPTION	*FASD-INFORMED REALITY*
Impulsivity	**Difficulty considering consequences and regulating responses before acting**
Selfishness	**Difficulty understanding others' perspectives and considering how their actions affect others**
Being stubborn	**May have concrete or rigid thinking**
Immaturity	**May develop social and emotional skills at a different pace than their peers**

Strategy: **Use concrete communication and examples**	**Teach social skills explicitly, breaking them down into concrete steps.**
Strategy: **Shift from anger to accommodation**	**Consider gaps in memory, development, understanding, and processing and look for supportive accommodations.**
Strategy: **Create structured social opportunities**	**Participate in organized group activities or supervised playdates. Provide clear guidelines and support during these interactions.**
Strategy: **Use visual supports**	**Utilize social scripts, cue cards, or visual schedules, can assist with understanding and navigating situations.**

Scan the QR code for nine reasons why visual supports are effective strategies for individuals with FASD.

Check out FASD Training Australia's video on brain-based reasons for "possessiveness" in people with FASD.

Decision Making

Addressing Challenges with Decision Making

What might be viewed as "poor judgment" is often the person doing their best in that moment. Prenatal alcohol exposure affects the brain in ways that can influence decision making, including impulsivity, lack of understanding of consequences, and difficulty recognizing social cues.

Common Misconceptions about Decision Making

PERCEPTION	*FASD-INFORMED REALITY*
Reactive	**Individuals may react without processing first, which can be misread as overreacting**
Defiant	**May have difficulty pausing to think through decisions before acting**
Lacks empathy	**May have difficulty understanding how their actions affect others**
Disrespectful	**May struggle to understand ownership and social expectations**

Strategy: **Practice simple communication**	**Use clear and simple communication, in addition to positive reinforcements, to encourage better choices.**
Strategy: **Be accommodating**	**Use mistakes as learning opportunities. Accomodate by providing structure, concrete language, and supervision.**
Strategy: **Use visual aids**	**Use visual aids showing alternative strategies for future situations.**
Strategy: **Give feedback in the moment (not later)**	**Keep explanations brief but clear. Don't wait until later to discuss the behavior (unless the individual is dysregulated).**
Strategy: **Be supportive**	**Use supportive prompts instead of criticism. For example, “Let’s think this through together” to problem solve.**
Strategy: **Stay calm**	**Maintain a calm and patient demeanor as much as possible. Co-regulate in stressful situations.**

Truth Telling/Honesty

Addressing Truth Telling/Honesty

What may appear to be lying is often confabulation—an unintentional neurological response where the brain fills in memory gaps by creating details or stories.[11] Unlike deliberate deception, individuals with FASD often believe these altered memories are accurate and are not intentionally trying to mislead others.

Common Misconceptions about Truth Telling/Honesty

PERCEPTION	*FASD-INFORMED REALITY*
Being dishonest	**May be experiencing confabulation or memory gaps (not intentionally lying)**
Manipulating	**May be responding to confusion or stress (rather than trying to control others)**
Trying to deceive	**May say what they think you want to hear to reduce conflict or misunderstanding**
Being defiant	**May not understand the situation and/or may have trouble regulating response**

Strategy: **Be curious, not confrontational**	Instead of saying, "That's not true," try saying, "I remember it a little differently. Let's figure it out together."
Strategy: **Interpret behavior as lack of understanding**	Confabulation and non-compliance should be interpreted as not understanding or forgetting.
Strategy: **Allow for extra processing time**	Allow extra time or suggest they think about it before answering, and then check for understanding.
Strategy: **Keep it simple**	Avoid using complex or multiple choice questions. Try to only ask one thing at a time.
Strategy: **Support memory gaps**	Review events together and use visual reminders. Write down key information they can refer to.
Strategy: **Educate others**	Help others (such as teachers or case workers) understand confabulation to reduce misunderstanding.

Sexuality

Addressing Sexuality

Many individuals with an FASD may have difficulty with emotional or psychological maturity, especially as they enter puberty and adolescence. This can make it hard for individual to understand and adhere to appropriate behaviors in sexual contexts, leading to behavior that may be considered inappropriate. Individuals with an FASD may find sexual relationships hard to navigate as well as have a difficult time understanding social norms related to sexuality.

Common Misconceptions about Sexuality

PERCEPTION	*FASD-INFORMED REALITY*
Being promiscuous	**May have difficulty understanding boundaries, consent, and social cues**
Behaving inappropriately	**May struggle with impulse control, social expectations, and recognizing context**
Not interested in sexuality or capable of sexual expression	**People with FASD are sexual beings with the same rights and same spectrum of needs and desires as anyone else.[12]**

Strategy: **Develop a safety plan together**	Create plans for different situations, including what to do if they feel unsafe or confused in social or sexual situations.
Strategy: **Have regular discussions about sexual health**	Tailor conversations about sexual health to the person's unique needs, strengths, and level of understanding.
Strategy: **Use direct and literal communication**	Be very clear regarding what types of sexual behaviors are appropriate and not appropriate, what consent is, etc.
Strategy: **Model social interactions**	For example, practice how to give or receive hugs. Talk about what would make a hug inappropriate and check for understanding.
Strategy: **Talk about and practice internet safety**	Supervise and guide their use of the internet to protect them from exploitation and inappropriate content.

Looking for more information and strategies? Check out this resource from Relationships Decoded.

Resources

The **FASD United Family Navigators** serve members of the FASD community (including parents/caregivers, people with FASD, and professionals) through one-on-one peer support, referrals to resources and services, information about prenatal alcohol exposure, or with a question about any facet of FASD. This service is free and does not require a referral.

FASD United offers a variety of **fact sheets about FASD**. They include topics like FASD basics, what to do after an FASD diagnosis, education, employment, mental health, and more. They can be downloaded, printed, and shared both online and in-person.

FASD United offers a comprehensive **Resource Directory,** where you can find resources across the country for individuals and families with disabilities. This includes information on resources for advocacy, family-centered care, FASD diagnosis, peer support, employment, education, and more. If you want help finding resources, please contact the Family Navigators.

Resources

Proof Alliance's Weekly Virtual Support Group provides a welcoming space for caregivers to connect, share experiences, and find support from others who understand the unique journey of caring for someone with FASD. All FASD caregivers are welcome!

"The Uncompromising Child: Four Responses to Rigid Thinking" is a resource by Ellen Devine. It provides four practical strategies for supporting children who struggle with flexibility, including reducing conflict, preparing for transitions, using concrete/visual supports, and helping children understand other perspectives.

"The FASD Self-Advocate Guide" is a resource created for and by individuals with FASD. It is designed to help individuals with PAE recognize their worth and understand more about themselves and their experiences navigating life with FASD.

"Glimpses of FASD" are short, personal stories that give the public a better understanding of what it's like to live with FASD. They provide an opportunity to hear directly from people with living experience and learn about their perspectives and everyday experiences.

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