Language & Stigma Guide

FASD United

2024

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About FASD United

FASD United's mission is to empower people living with FASD and prenatal substance exposure to educate systems of care and public, enact policies, and unite communities everywhere.

FASD United's vision is an FASD-informed world where people living with FASD and prenatal substance exposure are recognized and supported.

For over 30 years, FASD United has served as the national voice on FASD in the United States.

To learn more, visit FASDUnited.org

PART
ONE

Introduction

Tools for Effective and Respectful Communications about Fetal Alcohol Spectrum Disorders and Prenatal Alcohol Exposure

Introduction

Fetal alcohol spectrum disorders (FASD), a range of disabilities caused by prenatal alcohol exposure, are misunderstood and unrecognized by existing systems of care. With an increase in prenatal alcohol exposure (PAE)[1] and as many as 1 in 20 U.S. children having an FASD[2], the need to create FASD-informed systems is crucial. FASD awareness is low, which contributes to the ongoing stigma associated with FASD.[3]

To acknowledge the pervasiveness of stigma, this guide will explore its effects on healthcare and public policy, finishing with an overview of the areas of stigma. Each section will provide some context on how FASD and stigma are interrelated and pose questions to consider. Use these questions to examine beliefs and behaviors towards individuals with FASD or to start a conversation about how stigma can inform communication about FASD.

About This Guide

This guide is meant for the FASD community at large. Anyone who wants to discuss FASD and prenatal alcohol exposure publicly, in research, with other organizations, or in media will benefit from a deeper understanding of how language affects stigma. While much research is still needed on how stigma impacts FASD, this guide is informed by essential concepts from broader research on stigma and the collective direct experience of addressing stigma relating to FASD and prenatal alcohol exposure.

Stigma is widespread and must be addressed if systems of care and society are to become more FASD-aware and informed.

Why Does Stigma Matter?

People with FASD, their families, and those who consumed alcohol during pregnancy are often subject to stigma. This stigma can have negative impacts such as lower self-esteem, difficulties in social interactions, social isolation, reluctance to seek help, and discriminatory attitudes.[4] It can be a barrier when individuals who consume alcohol during pregnancy do not self-report alcohol use for fear of retribution or when individuals with FASD have their needs dismissed due to a lack of FASD awareness. The effect of stigma is apparent when doctors hesitate to diagnose FASD, fearing that it may cause more stigma for the parents and the individuals.[5] Stigma can also impact the availability of support, charitable giving, and political enthusiasm and advocacy.[6]

Why Does Language Matter?

Language is powerful. It impacts the way people think, act, and feel and can be a tool for creating a more FASD-informed world. How individuals and society as a whole communicate about FASD impacts attitudes and behaviors toward individuals and the field of FASD in general. It is crucial to proactively address stigma to provide better outcomes for individuals with FASD, their families, and those who consume alcohol during pregnancy. Encouragingly, research has shown that anti-stigma campaigns can lead to an increase in use of important services.[7]

Stigma can come from a lack of awareness and understanding. Accurate communication using non-stigmatizing language will raise awareness while countering misleading and inaccurate representations of FASD. The language one uses should be factual and not perpetuate negative stereotypes.

Reframe:

- FASD is not just an issue for women or specific groups
- Inclusive language is important to reduce blame and stigma

Key Themes:

- Health Equity
- Stigma Reduction
- Inclusiveness
- Positive Messaging
- Accurate Communication

Language is powerful and can impact attitudes and behaviors toward individuals or groups. With that in mind, the goal of this guide is to:

- Inform those writing and speaking about FASD so they can do so in a way that communicates information factually and respectfully.
- Aid people in communicating in a way that promotes a culture of support and respect.
- Promote FASD awareness and stigma reduction across all levels of care.

Inherent in this approach is a focus on the living experience of the FASD community rather than centering alcohol use during pregnancy. To do this, it is critical to promote the dignity and respect of individuals with FASD, their caregivers, and those who use(d) alcohol during pregnancy. This is done by avoiding blame or language that can perpetuate stigma and stereotypes. Supporting this approach is the use of research and fact-driven information, allowing for accurate communication and avoiding politicization and segmentation of the issue. These themes emphasize support rather than elimination and provide a message of hope and inclusion.

This guide has three main sections: *Preferred Language and Messaging*, *Use of Stigmatizing Imagery*, and *Conversation Starters on Stigma*. Subsections include *Definitions*, *Individuals with Living Experience*, *Families and Pregnant People*, *Discussing Statistics*, and *Research and Other Topics*.

The definitions section includes diagnostic terms, health equity and inclusivity concepts, and stigma considerations, and it will help provide a base level of knowledge that informs the rest of the guide and can be used for reference. There are two additional subsections that explain what language and imagery are non-preferred and include recommendations for less stigmatizing alternatives.

It is important to remember that FASD encompasses a range of disabilities. Throughout this guide, the general topic of fetal alcohol spectrum disorders is referred to as FASD, while the various disorders under the FASD umbrella are referenced as FASDs. For example, the use of the singular "FASD" when defining FASD-trained on page 6, and the plural "FASDs" when explaining that FASDs are not diseases. The critical takeaway is that FASD is an umbrella term, and its use implies the importance of all the disabilities it encompasses.

This guide recommends that communication should focus on prenatal alcohol exposure rather than the behavior of consuming alcohol. This approach is less stigmatizing and allows for discussion based on strengths, access to support, and FASD awareness. This guide also includes non-stigmatizing language suggestions for communicating about individuals who consume alcohol during pregnancy.

While this guide offers preferred language and tools for respectful and accurate communication, individual preferences might differ. More research on FASD-specific stigma is needed, so the information provided here will be updated as the understanding of the issue evolves.

PART
TWO

Preferred Language and Messaging

Preferred Language and Messaging

Definitions

This section features standardized definitions of terms surrounding FASD and stigma. While not all-encompassing, it does provide context for informed discussions on FASD, health equity, and stigma. Diagnostic terms have changed throughout the fifty years since the recognition of FASD in the United States[8], with some terms becoming less widely used (see "Alcohol-Related Birth Defects"). As more is understood about how FASD intersects with other issues concerning health equity, comorbidity, and diagnostic criteria, this list of definitions will need to be updated.

A theme that emerges through this section and the rest of the guide is the use of FASD as an umbrella term. This is done to allow the entire spectrum of disorders to be included in the discussions surrounding support, policy, and stigma. It also ensures that no single diagnosis is seen as more important than another, which can be a barrier to support. This is not to discount any diagnosis and is certainly not meant to negate anyone's experience of being diagnosed, but rather is part of the ongoing work to raise awareness of FASD in general.

Term	Definition
Access	The removal of barriers, like discrimination and lack of awareness, that cause inequity.[9] • An example of access is the ability to attend a medical or psychiatric appointment remotely rather than in person.
Alcohol-Related Birth Defects (ARBD)	ARBD is a diagnosis under the umbrella of FASD in which an individual shows at least one atypical physical feature attributed to prenatal alcohol exposure (PAE).[10] To receive this diagnosis, an individual must have documented PAE.
Alcohol-Related Neurodevelopmental Disorder (ARND)	ARND is a diagnosis under the umbrella of FASD in which an individual might have difficulties with intellectual, cognitive, or behavioral functioning. To receive this diagnosis, an individual must have documented PAE. • This term was first used in 1996 to describe neurodevelopmental disorders associated with PAE that did not present the physical characteristics of FAS.[11]
Bias	"A predisposition for or against something."[12] One might have a motivational bias when they draw conclusions based on self-interest or social pressure. One could also have a cognitive bias, which is a judgment that goes against evidence.
Fetal Alcohol Spectrum Disorders (FASD)	An umbrella term describing the range of effects that can occur in an individual prenatally exposed to alcohol. These effects may include physical, mental, behavioral, and/or learning disabilities with lifelong implications. The term FASD is not intended for use as a clinical diagnosis.[13] • Fetal alcohol spectrum disorders were defined by U.S. federal agencies, researchers, and field experts at the 2004 Fetal Alcohol Spectrum Disorders Terminology Summit.[14] • This definition has been revised using less stigmatizing, more inclusive language. The current definition replaces "in an individual whose mother drank alcohol during pregnancy" with "in an individual prenatally exposed to alcohol."[15]

Term	Definition
Fetal Alcohol Spectrum Disorders (FASD) (Continued)	• The physical effects of FASD are less commonly seen than the behavioral effects in individuals in clinical care.[16] This is not said to diminish the seriousness of the physical elements of FASD; instead, it is to avoid placing more importance on the physical facial features most related to Fetal Alcohol Syndrom (FAS). • It should also be noted that FASD is a diagnostic term in some places outside the United States.
FASD-Aware	An individual, institution, or system is FASD-aware when they have heard of FASD but may not completely understand the complexity and nuance of this disability.
FASD-Informed	An individual, institution, or system is FASD-informed when they are educated on the complexities and nuances of FASD. This includes an understanding of and appreciation for the experience of individuals with FASD and their families and caregivers and the stigma they experience. This can be contrasted with being FASD-aware and FASD-trained.
FASD-Trained	Being FASD-trained means an individual, institution, or system of care has been through FASD-specific training that allows them to serve the FASD community more intentionally and effectively.
Fetal Alcohol Syndrome (FAS)	FAS is a diagnosis associated with prenatal alcohol exposure in which an individual has atypical growth, central nervous system impairment, and specific facial features.[17] FAS was first used as a term in 1973 to describe the teratogenic effects of alcohol use during pregnancy and precedes the use of FASD.[18] Its early adoption as a term has caused it to become the most recognizable term in this field. • It is currently the only diagnostic term with widespread recognition among the public. • Only 10% of individuals with an FASD exhibit the characteristic dysmorphic facial features consistent with an FAS diagnosis.[19]

Term	Definition
Gender Identity	Describes a person's psychological sense of gender that may or may not align with the sex they were assigned at birth. This concept applies to everyone, not just individuals who are transgender or gender-nonconforming.[20]
Gender-Exclusive Language	Language that often generalizes everyone as masculine or assumes gender. When discussing a hypothetical person or people in general, it is best not to use gendered pronouns. Instead, one might use "they" or "them," an example of *gender-inclusive language*. When talking about a specific person, it is best to use the pronouns they use.
Generalization	Using a limited number of specific cases or insignificant evidence to draw conclusions or form a judgement or theory.[21] One might make a generalization about a group after learning something about one individual from that group.
Health Equity	"Ensuring that everyone has a fair and just opportunity to be as healthy as possible. This requires removing obstacles to health."[1]
Identity-First Language	Language in which disability is the focus. Identity-first language can allow individuals to control what others call their disability and is often used to "reclaim" terms. It is important to note that a person's preference should be prioritized. • An example of identity-first language is "autistic person", compared to "person with autism", which is person-first language. • It can be appropriate to use both person-first and identity-first language. Still, care must be taken to avoid stigmatizing language and placing undue weight on the disability rather than the person.

Term	Definition
Intersectionality	How various forms of discrimination overlap and combine in the experiences of marginalized groups. Intersectionality shows us that realities like classism, ablism, racism, and sexism cannot be understood fully in isolation but must instead be considered together.[22]
Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE)	ND-PAE is a diagnosis under the umbrella of FASD in the DSM-V's section on Conditions for Further Study. Four things are necessary for this diagnosis: 1) difficulty with neurocognitive functioning, 2) difficulty with self-regulation, 3) difficulty with adaptive functioning, and 4) the individual must have been prenatally exposed to more than minimal levels of alcohol as defined by the American Psychological Association.[23] This term was created for inclusion in the DSM-V, published in 2013.
Neurodiversity	A term used by groups with neurodevelopmental disabilities. Neurodiversity implies that society and levels of care should adapt to such disabilities as they are natural differences in brain functioning.[24]
Person-First Language	Language in which the person is centered, rather than their disability or experience. It is important to note that a person's preference should be considered and should dictate usage. • An example of person-first language is individual with autism, compared with autistic person which is identity-first language.
Prenatal Alcohol Exposure (PAE)	PAE is any in-utero exposure to alcohol during gestation. Alcohol is a teratogen that can cause developmental abnormalities, and there is no known safe amount that can be used during pregnancy.[25] One does not need to have an FASD diagnosis to have PAE.

Term	Definition
Prenatal Substance Exposure (PSE)	PSE is any in-utero exposure to a teratogen or drug. This includes alcohol, but PAE is often used as it is more specific.
Public Stigma	The cognitive, affective, and behavioral reactions towards individuals with an apparent condition.[26] An example of public stigma is the belief that children with mental health disorders are more likely to "get in trouble" than their peers.
Punitive Policy Punitive Strategy	A punitive policy or strategy attempts to enact change or respond to a social issue using punishment. As it relates to FASD, a punitive policy punishes pregnant persons who consume alcohol to decrease PAE within society. An example of this is classifying alcohol or substance use during pregnancy as child abuse or neglect.
Screening, Brief Intervention, and Referral to Treatment (SBIRT)	SBIRT is a comprehensive, integrated, public health approach to the delivery of early intervention and treatment services for persons with substance use disorders, as well as those who are at risk of developing these disorders. By incorporating SBIRT into routine healthcare, providers can not only offer timely interventions but also refer patients to additional treatment if warranted, helping to address alcohol misuse before it escalates into more severe issues.
Self-Stigma	The social and psychological effects of having stigma, which include the anticipation of being stigmatized and internalized negative beliefs.[27] Self-Stigma can affect self-worth and self-esteem. • An example of self-stigma is an individual's belief that they will not be successful in school because they have a mental disorder.
Spectrum	Spectrum refers to a group of diagnoses and behaviors that share symptoms. It does not imply severity or hierarchy but rather a continuum of symptoms.

Term	Definition
Static Encephalopathy, Alcohol Exposed	This is a diagnosis under the umbrella of FASD in which there is confirmed prenatal alcohol exposure and structural or functional central nervous system abnormalities, but no facial characteristics associated with FAS.
Stereotype	Cognitive generalizations about a particular group that are often exaggerated and negative.[28] • An example of a stereotype is the belief that parents of individuals with FASD have alcohol use disorders.
Stigma	"A set of damaging attitudes, stereotypes, and discriminatory behaviors."[11]
Stigma by Association	The social and psychological reactions to being associated with a stigmatized individual.[29] • An example of stigma by association is seen when the family member of an individual with FASD avoids social situations where they might need to talk about their loved one.
Structural Stigma	How society's prevailing thoughts and institutions perpetuate a stigmatized status.[30] • An example of structural stigma is punitive policies for consuming alcohol during pregnancy.
Supportive Policy Supportive Strategy	A supportive policy or strategy attempts to enact change or respond to a social issue using practices meant to educate and assist individuals.
Systems of Care	As defined by Stroul et al., effective, community-based services and supports that are organized into a coordinated network and build meaningful partnerships with families and individuals to help them function better throughout life.[31]
Teratogen	Any substance that causes congenital disorders in a developing embryo or fetus.[32] • Congenital: present at birth

PART
THREE

Individuals with Living Experience

Individuals with Living Experience

It is recommended that this guide be used as a starting point for preferred language and terms. It is important to note that everyone is unique, and many individuals diagnosed with an FASD prefer different terminology. For example, some individuals prefer “lived experience,” while others like “living experience.” While this guide can be used for general recommendations, it is best practice to ask individuals their preference.

A theme in the following sections is person-first language, or language that centers the individual rather than their disability. Many people with disabilities prefer person-first language because it emphasizes that they are first and foremost people, who are not solely defined by their disability. The Americans with Disabilities Act of 1990[33] and the Individuals with Disabilities Education Act of 1997[34] codified the use of person-first language into law. Still, it is always important to consider an individual’s preferred language. Some people prefer identity-first language because their disability is an important part of their identity. For example, many individuals within the autism community prefer being called "autistic" rather than "a person with autism" because their disability is an important part of their identity. [75] Whenever possible, inquire about individuals' preferred language, acknowledging that preferences may differ from person to person. In instances where preferences differ, it is useful to default to language that is respectful and focuses on strengths rather than limitations.

Best Practice!

- Use person-first language
- Emphasize individual's strengths
- Highlight the need for accessibility
- Avoid victimization and stereotyping

Often, when writing about disabilities, people tend to sensationalize them. This can come in the form of tear-jerking stories or anecdotes in which successful people with disabilities are made into heroes. Both examples can be damaging as the former perpetuates negative stereotypes by focusing on shortcomings rather than highlighting strengths, and the latter creates the narrative that everyone with a disability should try to inspire others. There are challenges associated with FASD, but these challenges are often magnified and made more difficult by stigma and a lack of support and awareness of FASD. Individuals with FASD have strengths that can be supported to help them thrive. Highlighting individuals' strengths and access to support promotes stigma reduction while raising awareness of FASD.

It bears repeating that the individual's preference is more important than these guidelines. It is recommended to ask people with FASD what their preferred language is, while keeping in mind that what one person prefers, another person might not. In such cases, defaulting to non-stigmatizing language or language that highlights strengths rather than weaknesses is helpful.

Non-preferred	Preferred	Reasoning
Behavioral Disorder	Spectrum of disorders Neurodevelopmental disorder Cognitive disorder Executive functioning disorder	FASD affects many facets of an individual, and undue emphasis on behavior can cause people to overlook or simplify a person's symptoms. Use of Behavioral Disorder can also lead to people interpreting willful maladaptive behavior.
Born Addicted Born Alcoholic Addicted Baby	Born with (an) FASD Born prenatally exposed to alcohol	It is not accurate or correct to state that a baby is born addicted. There is evidence that using medical terms can reduce stigma, and it is medically accurate to say a baby was born prenatally exposed to alcohol.[35]
Brain Damage	Individual with a brain injury	Person first language. It should only be used when referring to an actual brain injury, not developmental delays.
Disease Syndrome	Disorder Disability	Correct terms are disorder and disability, as FASDs are not diseases. Using the word "syndrome" is only appropriate if referencing FAS. Referring to FASD in general as a syndrome places too much focus on FAS compared to other diagnoses.

Non-preferred	Preferred	Reasoning
FASD kid FASD victim FAS-ling Person Damaged by FASD Person Living with FASD Suffering With, Afflicted by, or Victim of FASD	Individual diagnosed with an FASD Individual with FASD Individual with PAE	Person-first language does not focus on the disability or the diagnosis and does not assign blame or imply a burden. "Victim," "damaged by," "living with," "suffering with," and "afflicted by" all imply a burden or assign blame. "FAS-ling" is infantilizing. • Note the use of "individual" rather than "child," as FASD is a lifelong disability. • Referring to a person "with an FASD" generally means that the person has been diagnosed with a specific FASD, while referring to a person "with FASD" is inclusive of those that do not have an official diagnosis.
Fetal Alcohol Effects (FAE)	FASD	FAE is an older term that was used before the term FASD. The Institute of Medicine replaced the term FAE with ARND and ARBD in 1996.
Fetal alcohol spectrum disorder, FAS, ARND, ARBD, ND-PAE Non-preferred is identifying a person by emphasizing that a person has a specific diagnosis under the FASD umbrella. Example: "We will hear from a young adult with ND-PAE."	FASD Example: "We will hear from a young adult diagnosed with an FASD."	Avoiding the term fetal allows for a broader discussion in which FASD is accurately seen as a lifelong disorder. It also prevents associating FASD with unrelated topics like abortion. While citing a specific diagnosis can be appropriate in certain situations, it can create a hierarchy of disabilities within FASD. This can function as a barrier to support for those with symptoms that are not physically apparent. • Unlike other countries, the US does not use FASD as a diagnostic term. • When communicating with a group that is unfamiliar with FASD, it is appropriate to refer to fetal alcohol spectrum disorder.

Non-preferred	Preferred	Reasoning
Full FAS Full FASD Full-Blown FAS/ FASD	FASD	Sometimes, “full FASD” is used to differentiate from partial FAS, but this is problematic and can be stigmatizing and confusing. It also creates a hierarchy of disabilities that can create barriers to support and places undue emphasis on the noticeable physical element of FAS.
Invisible disability Hidden disability	Non-apparent disability • Talk about the prevalence of FASD compared to the awareness of FASD and how that is a barrier to supports	Invisible/hidden can minimize the issue and disregard the experience of individuals with FASD.
Lies Lying Purposeful deception	Confabulates Lacks impulse control or the ability to give completely accurate accounting in the time provided	Confabulation implies no intent to deceive or act maliciously and highlights memory challenges associated with FASD.
Lived Experience	Living Experience	Living experience emphasizes an individual’s ongoing experience and that FASD is lifelong rather than just a childhood experience.
Low Functioning High Functioning	Focus on the supports needed or strengths possessed by the individual	It puts the focus on the individual and is less stigmatizing. Support needs do not range from low to high but vary by individuals’ strengths, challenges, and characteristics.

Non-preferred	Preferred	Reasoning
Meltdown	Sensory overload Dysregulation due to unsupported needs	Avoids infantilizing language.
Mental Retardation	Intellectual Disability	It avoids the negative connotations of the term “retarded,” which is a harmful slur. Specific federal laws referencing mental retardation have changed the language to intellectual disability.
Mentally Disabled	Individual with cognitive or neurodevelopmental disability	Person first language, less stigmatizing.
Non-Compliant Will not Comply	Unable to comply	Behaviors associated with FASD are not intentional or willful, but are the product of a disability.
Normal Normative	Neurotypical	Everyone is different, and there is no true normal. This is less stigmatizing.
(Other Diagnosis) With FASD	They have an FASD with associated (insert another diagnosis here)	Highlights FASD as a primary diagnosis and ensures that supports and interventions will be FASD-informed.
People With FASD Are...	Avoid generalizations	Individuals with FASD are impacted differently, have unique abilities, and need unique supports.

Non-preferred	Preferred	Reasoning
Poisoned in the Womb	Prenatally exposed to alcohol	Less stigmatizing, more accurate.
Saying that a person "looks like they have FASD or Fetal Alcohol Syndrome."	Avoid generalizations and talking about appearances unless it is medically relevant.	FASD and FAS are not a "look" and are not defined by one's physical appearance. This language is stigmatizing, especially when it is used to cause insult.
Severe FASD/FAS	Focus on the supports needed or strengths possessed by the individual.	The word "severe" can be stigmatizing and negative.
Suffer From FASD Afflicted With FASD	Diagnosed with an FASD, Individual with FASD, Individual with PAE	Fails to value positive attributes and strengths. Avoid harshly negative language that catastrophizes the condition or conveys a sense of doom and gloom.
Suspected FASD	Possible FASD	"Suspected" has negative connotations often associated with wrongdoing.
"The FAS face"	Specific facial features related to fetal alcohol syndrome Facial dysmorphology Sentinel facial features	Referring to "the FAS face" can be both stigmatizing and objectifying and is an oversimplification of a complex and nuanced topic.
Victims of FASD "They have FASD through no fault of their own."	Individuals with an FASD Born with an FASD Born prenatally exposed to alcohol	Avoid using "victim" language that implies that there is a malicious perpetrator or that someone is at fault for FASD. This does not aid in the prevention of prenatal alcohol exposure or in supporting families seeking diagnosis or support for their family members. Fault implies punitive measures are needed.
Violent, Misbehaves, or Acts Out	Dysregulated Has issues with impulse control	FASD can affect executive functioning, impulse control and decision-making.[36] Avoid terms which imply intentional negative behavior.

PART
FOUR

Families and Pregnant People

Families and Pregnant People

It is important to use non-judgmental language when discussing families. Using inclusive language can reduce incorrect and sometimes harmful assumptions about identities and behaviors. A theme in this guide, in addition to person first language, is the use of terms that do not assign blame or imply personal failure. Often, when communicating about families living with FASD, there is a tendency to use language that emphasizes the behavior of the birth parent(s), implying blame and causing the family to feel stigmatized.

By using less stigmatizing language, the same information can be conveyed in a way that uplifts and affirms families. For example, to say that "FASD is caused by a pregnant person drinking" assigns blame. Instead, saying "FASD is caused by prenatal alcohol exposure" is accurate and does not emphasize the behavior of the pregnant person, helping to remove the implication of blame.

It is recommended that this guide be used as a starting point for preferred language and terms related to families and pregnant people. Individuals may prefer different terminology than others, and it is best practice to ask for individual preference. For example, some individuals in the 12-step community prefer to identify themselves as a "recovering addict" while others like to say they are "a person in recovery" or a "non-drinker." It bears repeating that the individual's preference is more important than these guidelines. Ask individuals what their preferred language is while keeping in mind that what one person prefers, another person might not. In such cases, defaulting to non-stigmatizing language or language that highlights strengths rather than weaknesses is helpful.

Non-preferred	Preferred	Reasoning
Admitted to Using Alcohol or Substances	Confirmed prenatal alcohol exposure	It is less stigmatizing and does not assign undue blame. It is important to focus on prenatal alcohol exposure and not the behavior of consuming alcohol.
Alcoholic, Addict	Person with an alcohol use disorder Person with a substance use disorder	Less stigmatizing, person-first language.
Clean	In recovery. Not drinking or taking drugs. Abstinence from drugs or alcohol.	It avoids the implication that someone who drinks or uses drugs is "dirty." there is evidence that using medical terms can reduce stigma.[37]
FASD Family	Family affected by FASD	This language puts the people before the disability.
FASD is caused by a person drinking during pregnancy	FASD can occur when a developing fetus is exposed to alcohol.	Does not assign undue blame and balances support with prevention.
Mother Pregnant Woman	Pregnant person Pregnant people Birthing parent People able to become pregnant	Not all individuals who can become pregnant identify as women. The goal is not to dehumanize those who identify as women but instead to be inclusive of all people who may become pregnant.

Non-preferred	Preferred	Reasoning
Substance Abuse Alcohol Abuse	Substance use	It is less stigmatizing and does not imply willful wrongdoing.
Tribal Tribe American Indian Indian	Describe Indigenous individuals by using their specific preferred Native nation affiliation (i.e. "Diné" or "Ojibwe"). When talking about *multiple* nations, it is generally appropriate to use Indigenous for individuals and Indigenous Peoples or Native nations for groups. Depending on which nations one is referring to, it may be appropriate to say Native American, Alaska Native, Native Hawaiian, or First Nations.	Acceptable terminology varies by geographic location and context. Overall, the correct way of referring to a people is the term they themselves prefer. Note: While "Tribal" is used by certain parts of the government and in certain treaties, it is more accurate and helpful to refer to the specific names different nations have for themselves. Any use of "Tribal" in this guide is a direct quote.
Unborn Baby	Refer to the stage of development rather than a future stage of pregnancy. • Eight weeks after the last menstrual period: embryo • After eight weeks through delivery: fetus	It is more accurate, avoids potential stigma towards pregnant persons, and avoids connotations to unrelated issues like abortion.

PART
FIVE

Statistics, Research, and Other Topics

Statistics, Research, and Other Topics

This section provides communication strategies and preferred language on various topics related to FASD and alcohol-exposed pregnancies. While not an exhaustive list, this section covers a wide swath of topics common within the FASD community. Of note is the importance of accurate and specific language when using statistics and research, as well as the avoidance of generalizations.

Some of the "attention-grabbing" language that has been used in past FASD awareness messages was ineffective and, at times, harmful. For example, using extreme or "all-or-nothing" language like "100% preventable" or "even one drink" can grab attention, but this comes at the expense of accuracy and can perpetuate stigma. Proscriptive language like "do not drink during pregnancy" may sound strong and assertive, yet it often provokes a negative backlash. It is recommended to use language that avoids perpetuating stigma while being accurate and non-judgmental.

It is also important to provide context and nuance when discussing FASD. For example, FASD is often discussed in the context of criminal justice, foster care, and Indigenous populations. While these are important areas for FASD-informed support, without proper nuance it may be assumed that FASD is limited to these contexts alone, perpetuating misinformation, stigma and bias. It is important to make clear that FASD is prevalent within every population and in every aspect of society.

Best Practice

- Use accurate and specific statistics, avoid generalizations
- Be careful of "attention grabbing" language
- Avoid "all or nothing" language
- Avoid "should" language
- Nuance and care are needed when looking at specific contexts of FASD

Issue/Topic	Research	How to Communicate/ Takeaway	Why it Matters
"100% preventable"	41.6% of pregnancies were unplanned in 2019 according to the CDC.[38] Many people consume alcohol until they confirm they are pregnant.[39]	There are many social drivers of health that can influence PAE. • Through universal screening, education and support, and by focusing on the strengths of people with FASD, we can reflect the nuances needed to support prevention efforts without increasing stigma. • When speaking on prevention, it is important to acknowledge that prevention is possible, but 100% prevention is unrealistic.	"100% preventable" language can also be stigmatizing as it places blame on pregnant persons and ignores the social drivers of health that influence PAE. • People do not want to be prevented. Hearing that they should be prevented can affect a person's self-worth. It is recommended to focus on preventing PAE, not FASD.
Accuracy of statistics		Whenever referring to a specific number, such as "60% of people with FASD…" be sure to have a credible source for the statistic. Only use terms such as "most" when you have data showing that this applies to over 50%.	Accuracy and honesty are crucial when discussing topics like FASD. Effective, accurate communication allows for the best outcomes for all.

Issue/Topic	Research	How to Communicate/ Takeaway	Why it Matters
Adoption and foster care	It is estimated that nearly 80% of infants in foster care have been prenatally exposed to substances.[40] Youth diagnosed with an FASD are 9x more likely to be in foster care than those without FASD.[41]	As the prevalence of FASD within the foster care system is unusually high, foster care/ adoption personnel need FASD training and education to support this population best. The foster care system must be FASD-trained.	It is important to avoid the myth that adoptive parents as a group are more caring than biological parents. Avoid framing them as rescuers, which victimizes the birth family.
Alcohol Use Disorders	Alcohol use disorder is a chronic disease. Nearly 90% of people who drink excessively do not meet the criteria of having a severe alcohol use disorder.[42]	Alcohol use disorders have unique challenges and stigma attached that make PAE prevention even more complex. It is important to remember that FASD does not only occur due to alcohol use disorders and that people with alcohol use disorders deserve compassion and support, not blame or stigma.	We should avoid further stigmatizing alcohol use disorders and mischaracterizing PAE as something that only affects those with alcohol use disorders.
Amount of alcohol that can lead to FASD	"The risks of light-to-moderate drinking during pregnancy are readily demonstrable in preclinical studies and some clinical studies."[43]	There is no safe amount of alcohol consumption or PAE during pregnancy.	The risks of alcohol use during pregnancy far outweigh any potential perceived benefits, such as stress relief or temporary relaxation. Messaging contrary to this not only misinforms but also disregards over 50 years of research documenting the serious risks associated with PAE.

Issue/Topic	Research	How to Communicate/ Takeaway	Why it Matters
Do not drink while pregnant	No amount of alcohol is safe during pregnancy.[44]	Drinking any amount of alcohol while pregnant can lead to FASD. It is safest to avoid alcohol if you are pregnant or trying to become pregnant.	Drinking alcohol during pregnancy can lead to FASD. To support the health of both parent and baby, it's safest to avoid alcohol if you're pregnant or trying to conceive, without placing blame or shame.
FASD and comorbidity with other disabilities	"There are 428 conditions that can occur in individuals with FASD."[45]	Individuals with FASD may have other diagnoses, making each person's abilities unique.	Individuals with FASD require FASD-informed interventions. An intervention that works for an individual with a primary diagnosis of ADHD might not be as effective for an individual with a diagnosis of FASD and associated ADHD.[46]
FASD as an individual or family issue	FASD is not rare and impacts up to 1 in 20.[47]	FASD impacts society at every level and needs to be addressed at every level of society. With a prevalence of 1 in 20, the likelihood of knowing someone with an FASD is incredibly high.	FASD needs to be addressed across all systems of care. It is unfair and ineffective to place responsibility on individuals and families directly impacted by FASD.

Issue/Topic	Research	How to Communicate/ Takeaway	Why it Matters
FASD prevalence in the United States	"...the most conservative prevalence estimate of FASD was found to be as many as 1 in 20 first-grade students."[48]	As many as 1 in 20 children may have an FASD in the US. These children grow into adults with an FASD.	FASD is more prevalent than many believe. For some to take it seriously, its prevalence must be accurately communicated. It is important to remember that FASD does not only affect children.
FASD prevalence within specific populations	"The estimated prevalence of FASD in these special subpopulations (children in care, correctional, special education, specialized clinical and Aboriginal populations) was 10 to 40 times higher compared with the 7.7 per 1000 global FASD prevalence in the general population."[49]	There are higher rates of diagnosed FASD within certain special populations. This means that more aspects of society need to be FASD-informed, not that FASD is only an issue for select groups.	All aspects of healthcare and systems of care must be FASD trained as those most likely to be impacted by FASD will rely on or have contact with these systems. The rates of **diagnosed** FASD are higher in these populations, which does not inherently mean there is more FASD present within these communities, just that it has been screened for and diagnosed more. 19

Issue/Topic	Research	How to Communicate/ Takeaway	Why it Matters
Financial cost of FASD	A 2018 international review found the mean annual cost of care for children with an FASD to be an estimated $22,810 and $24,308 for adults.[50]	Apart from the impact FASD has on the lives of individuals and families, systems of care and various levels of government incur costs associated with FASD, especially when it goes undiagnosed and untreated. With proper systems of care and early intervention, there can be a decrease in both adverse outcomes for individuals and the annual cost of care.	Individuals, families, and the social welfare and health care systems incur costs related to FASD that could be minimized if adequate FASD-informed supports are provided. It is important to note that people have innate value and worth far beyond any costs they may have on systems of care.
Gun violence and FASD in the United States	No research exists showing that individuals diagnosed with FASD engage in gun violence more than others.	There is a need for stigma reduction within the justice system, as well as in the way the media portrays individuals diagnosed with FASD.	Misrepresentation and sensationalized reporting can be stigmatizing and lead people to make harmful generalizations.
Involvement with the Justice System	Individuals with FASD experience many challenges, leading to a disproportionate amount of youths with FASD coming into contact with the criminal justice system.[51]	The prevalence of FASD within the criminal justice system shows the need for change within the system and an increase in support.	Lack of adequate support can lead to adverse outcomes like involvement with the justice system. Without an informed justice system, individuals with an FASD have an increased risk of having their actions and behaviors misunderstood and mischaracterized.

Issue/Topic	Research	How to Communicate/ Takeaway	Why it Matters
Native/ Indigenous populations	"Some studies report higher rates of children with an FASD in Tribal communities compared with the general population."[52]	The prevalence of FASD within Indigenous communities is difficult to ascertain as it has only been studied in a few specific communities. It is important to note that forced separation policies and other forms of historical and ongoing trauma have caused children in Indigenous communities to be more likely to enter the child welfare system compared to non-Indigenous children.[53] Contact with the child welfare system increases the chance of receiving an FASD diagnosis, thus elevating prevalence rates.	FASD is not limited to any one community. FASD crosses all boundaries and cannot be considered an issue that primarily impacts one community more than another. Some communities are at the forefront of documenting PAE and identifying supports, which can also inflate prevalence. While many Indigenous communities have faced similar challenges and experienced similar traumas, it is generally not recommended to speak in broad generalizations about them rather than as distinct, individual Nations or communities.[54]
One drink can cause FASD	There are risks involved with light to moderate drinking during pregnancy.[56]	No amount of alcohol is safe during pregnancy.	Avoid emphasis on specific quantity, like "a single drink," and instead share evidence-based information about the effects of PAE. This is more accurate and reduces misinformation.

Issue/Topic	Research	How to Communicate/ Takeaway	Why it Matters
Non-alcoholic beer and other borderline examples (kombucha, hand sanitizer, communion wine)	Research has shown that no amount of alcohol is safe during pregnancy. One study has shown that beverages claiming to be no-alcohol or low-alcohol contained higher levels than declared.[55]	While no amount of alcohol consumption is safe during pregnancy, there is no firm, documented threshold of alcohol consumption that leads to FASD. Non-alcoholic beer and Kombucha in the U.S. must contain less than 0.5% alcohol, but some have been found to contain more alcohol than declared. The safest option is to abstain. For alternatives, we recommend opting for labels with "alcohol-free" rather than non-alcoholic, low-alcohol labels.	It is important to communicate about these things honestly. Some will swap out alcoholic for non-alcoholic beverages during pregnancy, and it is important to have open, honest conversations about that. Rather than getting into the details of something particular like kombucha, it is best to focus on the general message that no amount of alcohol is safe during pregnancy
Pregnant people should not drink.	There is no known safe amount of alcohol during pregnancy.	The safest choice is to avoid alcohol during pregnancy.	Avoid using "should" language because this implies that there is a rule being set and that those who violate the rule deserve some punishment.

Issue/Topic	Research	How to Communicate/ Takeaway	Why it Matters
Prevention	As there is no known safe amount of alcohol one can be prenatally exposed to, the only way to prevent PAE is through abstinence.[57]	Highlight the importance of preventing PAE, not FASD. Additionally, it can be helpful to view early identification and availability of support as prevention. Early diagnosis and access to FASD-informed support can prevent adverse experiences throughout life.	It is recommended to focus on preventing PAE, not FASD. Hearing language that suggests people with disabilities should be prevented can be dehumanizing. There is need for efforts that both prevent PAE and support those impacted.
Underage drinking, too young to drink	No evidence links underage drinking to FASD prevalence.	The highest rate of reported alcohol use among individuals able to become pregnant is from individuals aged 35-44 years.[58]	Avoid conflating FASD with the very different issue of underage drinking. A focus on PAE rather than the behavior of consuming alcohol is preferred. Underage drinking does not imply the intent to cause harm; avoid the use of imagery that suggests this.
Violent crime and FASD in media	No research exists showing that individuals with FASD engage in more violent crimes compared to those without.	Media tends to sensationalize stories involving individuals with FASD and do not highlight positive stories.	Misrepresentation and sensationalized reporting can be stigmatizing and lead people to make harmful generalizations.

PART
SIX

Use of Stigmatizing Imagery

Use of Stigmatizing Imagery

Just as with language, the use of imagery can be stigmatizing. Because images and words can be powerful communication tools, it is important to make sure people with FASD and their families are portrayed in a positive manner. Stigmatizing imagery within FASD literature, media coverage, and prevention campaigns has occurred since FASD was first recognized in the U.S. This type of imagery can cause harm and should be avoided.

When using images in FASD communications, it is best to portray individuals with FASD in a way that does not set them apart as different, which can feel othering or alienating. These four questions can be helpful in selecting images for use in FASD communications:

- Does this perpetuate a negative stereotype?
- Does this image imply willful negligence or neglectful behavior?
- Will this image alienate the population it is representing?
- Is this image scientifically accurate?

On the following pages, there are examples of how to best portray pregnant people. Professor Quill R. Kukla of Georgetown University and Editor-in-Chief of the Kennedy Institute of Ethics Journal shares the concept of the "headless pregnant person." Kukla states that rather than showing "pregnant people represented in their full living contexts," we see them as "disembodied, impersonal sites of reproduction."[59] It is therefore recommended to use images of full-bodied pregnant people in social settings to show them as part of society rather than a "site of reproductive risk and control."

Headless photos like the ones on the left reduce pregnant people's humanity. Photos that show pregnant people "in their full living contexts," such as the photos on the right, are much more humanizing and affirming.

Topic	Preferred	Non-preferred	Reasoning
Alcohol/Substances	Conceptual images, like molecular symbols for alcohol or specific substances. It is best to avoid all alcohol imagery, including bottles of alcohol or people consuming alcohol.	Individuals consuming alcohol or substances. Depictions of alcohol or substances.	Participants in a study labeled depictions of alcohol and other substances as triggering and stigmatizing.[60]
Diversity	Use images appropriate for the population being served. For general use, do not unduly overemphasize one group more than another.	Portraying FASD as an issue for only certain groups.	It would be misleading not to represent all groups and would be harmful and stigmatizing to overemphasize FASD in specific populations.
Embryo or fetus in the womb	Medically correct imagery.	Embryo, fetus, or baby in pain or surrounded by alcohol.	It is important to be factual and accurate when communicating and not to sensationalize. The non-preferred imagery can be stigmatizing and misleading. There is evidence that using medical terms can reduce stigma.[61]
Headless pregnant person or disembodied pregnancy	Full bodied pregnant person - including face.	Headless pregnant person.	Objectifying and dehumanizing.

Topic	Preferred	Non-preferred	Reasoning
People diagnosed with FASD	Positive images show individuals thriving and highlighting strengths.	An emphasis on those with physical disabilities. Images showing individuals in jail, committing crimes, or engaging in risky or harmful behavior.	It is essential to show how individuals can thrive when accommodated with the appropriate support.
Pregnant person drinking	It is best to avoid images of pregnant individuals consuming alcohol.	Obviously pregnant people (i.e. those in the third trimester) drinking. Portraying people drinking as "low class" or perpetuating the stigma of addiction.	FASD can occur prior to recognition of pregnancy.[6] Using images of obviously pregnant people places the responsibility solely on the pregnant person while also misrepresenting how FASD can occur. FASD is often mischaracterized as a gendered issue, which is damaging and incorrect. It is best to avoid this imagery altogether as it is negative.
Shocking/ scare tactic imagery	Use a strengths-based approach to share healthy portrayals of pregnancy.	Any graphic images meant to scare or shock people into not drinking while pregnant. Example: fetus/ embryo/baby floating in alcohol, babies drinking alcohol, any severe injuries	While it is unclear whether fear-based appeals are effective in raising awareness for FASD, the stigma concerns are valid. Even though fear-based appeals are effective for issues like smoking cessation, the potential for further stigma makes it inappropriate for FASD. • Fear-based appeals can be harmful by: • Labeling and stigmatizing. • Reinforcing existing disparities in society. • Reducing FASD to an individual's issue while ignoring societal factors.[62]

PART
SEVEN

Conversation Starters

Conversation Starters

It is important to talk about stigma and how it relates to FASD. Consider evaluating both personal and societal attitudes and behaviors towards individuals with FASD, their caregivers, and those who consume alcohol during pregnancy. Use this section as a starting point for thoughts and discussions to think critically about the role stigma plays in access to support, public policy, and the day-to-day lives of individuals.

Stigma and Healthcare

Stigma within the healthcare system acts as a barrier to support and diagnosis for individuals with FASD and their families and caregivers. Multiple surveys have shown that healthcare providers believe a diagnosis related to FASD will be stigmatizing.[63] While addressing the issue of stigma as it relates to diagnosing FASD is complex, there are steps healthcare providers can take to increase positive outcomes for pregnant people who consume alcohol. Doing so will educate patients on PAE and lessen the stigma associated with FASD and PAE.

Best Practice

- Be Transparent
- Use Non-Judgemental Language
- Educate with Care
- Regularly Screen for Alcohol
- Keep Messaging Consistent

CDC-funded research by Oak Ridge Associated Universities surveyed healthcare professionals' and patients' attitudes regarding alcohol use during pregnancy.[64]

The research team provided communication guidelines to equip healthcare professionals better to talk about alcohol use during pregnancy through screening, brief intervention, and referral to treatment practices (SBIRT). This research shows that 83% of healthcare professionals who routinely conducted screening and brief interventions reported a positive change in their patients, highlighting the importance of effective communication.

Before reading about successful messages for healthcare providers to use with their patients, consider the following:

- How could a misdiagnosis or lack of diagnosis lead to more stigma?
- Who would this stigma affect?
- What role should healthcare providers play in minimizing stigma?
- How would individuals benefit from the healthcare system being FASD-trained?

The research shows that patients value healthcare professionals' guidance in this field, and an overwhelming majority of patients reported wanting to learn more about alcohol use during pregnancy. To do this successfully, healthcare professionals should be transparent about the knowns and unknowns of alcohol use during pregnancy, talk about prenatal alcohol exposure within the overall context of mental health and healthy habits, and use non-judgmental language.

Patients and healthcare professionals both found transparent messaging helpful in seeing healthcare provider guidance on alcohol use as absolute rather than confusing the issue. Discussing alcohol use during pregnancy as part of the patient's mental health and overall healthy habits can expand the issue and decrease stigma as the focus is taken off the possibility of FASD. The CDC has identified successful messages to deliver during SBIs to people who can become pregnant and they have a full list of their recommendations in their 'Let's Talk' Guide. The guide includes evidence-based strategies and communication tips for healthcare providers to effectively discuss alcohol use with individuals who may become pregnant.

Questions to consider:

- How can discussing alcohol use in the context of overall physical and mental health avoid stigmatizing the issue?
- What are some examples of judgmental and non-judgmental language?

Stigma and Public Policy

Davis et al. (2023) looked at data ranging from 1972 to 2016 to assess the efficacy of policies related to alcohol use during pregnancy.[65] The authors specifically looked at how both *supportive policies and punitive policies impacted alcohol use during pregnancy*.

Stigma and Public Policy Continued

A study published in 2019 (Roberts et al.) showed that forty-three states had punitive or supportive laws regarding alcohol during pregnancy.[66] Fourteen states employed only supportive policies, such as mandatory warning signs, priority substance use treatment for pregnant persons with and without children, prohibitions on criminal prosecutions, and reporting requirements for data and treatment purposes. Four states used only punitive policies, like civil commitment, reporting requirements for use by Child Protective Services, and categorizing alcohol or substance use during pregnancy as child abuse or neglect. Twenty-five states used a mix of both punitive and supportive policies.

The data collected by Roberts et al. showed that pregnant adults in states without policies regarding alcohol use during pregnancy had a lower likelihood of incidents compared to states with such policies. Another study looking at data from 1972 to 2013 (Subbaraman et al., 2018) further showed an increase in the likelihood of adverse birth outcomes such as low birth weight, premature births, and an increased need for late prenatal care in states with punitive policies.[67] These states used a range of policies such as mandatory warning signs, requirements for reporting child abuse and neglect, priority treatment for pregnant persons, civil commitment policies, and defining alcohol use during pregnancy as child abuse or neglect.

Before moving on in this discussion, consider the following:

Ask Yourself

- Which type of policy, supportive or punitive, will most likely focus on an individual's needs?
- Are there policies that make individuals less likely to seek support?
- Can a punitive policy be successful if it leads to more stigma?

Why is it that state policies addressing alcohol use during pregnancy do not seem to be effective in curbing the practice?

Firstly, punitive policies perpetuate negative stereotypes and increase stigma. Supportive policies can also contribute to negative stereotypes, and their impacts can vary between racial groups who may experience different, racialized outcomes. These policies can attribute blame and place responsibility solely on those able to be pregnant. This leads pregnant individuals and parents to avoid seeking help for fear of retribution.

Secondly, the focus should be on implementing policies that allow the healthcare system to use practices promoting alcohol-free pregnancies. One such practice is screening, brief intervention, and referral to treatment (SBIRT), a routine preventive practice effective at reducing alcohol and other substance use for adults without an alcohol or other substance use disorder.

Supportive vs Punitive Policy:

- *Supportive* = assisting and educating those affected
- *Punitive* = addresses using punishment

This practice is non-stigmatizing and requires only positive reinforcement of low-risk behaviors. Policies making it easier for healthcare organizations to practice SBIRT could lead to improved outcomes and lower rates of alcohol and other substance use during pregnancy.

This analysis highlights the need for more research to identify policies that will reduce prenatal alcohol consumption. It also highlights the fact that alcohol use during pregnancy, and FASD in general, is not just an issue for pregnant persons or those with FASD; all systems of care must be FASD-informed. Responsibility for increasing positive outcomes must be shared, and providing support for those affected by prenatal alcohol exposure is crucial.

Other Areas of Stigma

Stigma is associated with many adverse outcomes, like lowered self-worth, decreased self-esteem, negative interactions with healthcare, and a decreased likelihood of seeking treatment. Much of the discussion surrounding stigma centers on *public stigma*, but we should also consider *self-stigma*, *stigma by association*, and *structural stigma* (definitions on pages 17 and 18). An example of public stigma is the belief that parents of individuals with FASD are bad parents. Self-stigma can manifest as an internalization of stereotypes or even the anticipation of being discriminated against. Stigma by association is seen when a family member of an individual with FASD isolates themselves from the community. Punitive policies towards individuals who consume alcohol during pregnancy are examples of structural stigma.

With these areas of stigma in mind, consider the following questions when communicating about FASD.

- How will this language or image make people feel about FASD?
- Will this language or image accurately reflect science and the living experience of FASD?
- Will this message highlight the strengths of individuals with FASD?

Public stigma, self-stigma, structural stigma, and stigma by association are interrelated and feed into each other. Public stigma can lead to more self-stigma and structural stigma. Structural stigma can also lead to more public stigma and self-stigma. Research has revealed three themes regarding stigma and FASD: personal responsibility or blame towards pregnant people who consume alcohol, felt stigma experienced by individuals and their families, and anticipated life trajectories of individuals with FASD.[30]

Consider 4 Areas of Stigma:

- Public Stigma
- Self-Stigma
- Stigma by Association
- Structural Stigma

Those who consume alcohol during pregnancy are often blamed and have feelings of shame that can cause negative self-perception. These feelings might dissuade them from disclosing alcohol use, thus preventing early monitoring or intervention. Focusing on blame and an overemphasis on prevention rather than support perpetuates the "bad parent" stigma that surrounds pregnant persons who consume alcohol. This is why it is best to focus on supporting those affected by prenatal alcohol exposure rather than focusing on the behavior of consuming alcohol.

While specific research on the experience of stigma for individuals with FASD is needed, research on other neurodevelopmental disorders shows the impact of stigma. For instance, a diagnosis of ADHD has been shown to affect parents' and teachers' perceptions of individuals with ADHD, and children diagnosed with ADHD have reported being perceived by teachers and classmates as unintelligent or different.[68] Individuals with FASD may, therefore, feel misunderstood, have their abilities underestimated, and be blamed for their learning challenges. Besides harming an individual's mental health, this stigma can be a barrier to much-needed support.

Individuals with FASD are sometimes seen as being fated to have negative life trajectories. When this idea is perpetuated, stigma is created. This false perception of life trajectory opposes research showing that children with adequate support and advocacy experience success and persist in school. These false perceptions of life trajectories lead health and social policies to view the challenges associated with FASD as unavoidable rather than fixable.

With these examples in mind and an understanding that public stigma, self-stigma, and structural stigma are intertwined and feed into each other, consider these questions:

- **Are my attitudes towards FASD based on real-life interactions and experience?**
- **Does how I act make people feel "different" or label them as "others"?**
- **What role am I playing in perpetuating or stopping the cycle of stigma?**

This guide is a resource for promoting respectful and accurate communication by drawing attention to preferred language and tools to navigate conversations related to FASD. The need for stigma reduction is clear, and the language used can be an effective tool. Reframing how we communicate will help others reframe their thinking, leading to a more FASD-informed world. The goal of this Language and Stigma Guide is to assist in evaluating communication about FASD and how that might impact public perception. By staying coordinated with recent developments and research in our understanding of this issue, we can ensure that our communication practices remain respectful and responsive to fit the diverse needs of individuals affected by FASD.

Thank you to the following organizations for the work they have done regarding FASD stigma and language, which has helped shape and inform this guide:

- CanFASD and the Canada Northwest FASD Partnership[69]
- The National Organisation for Fetal Alcohol Spectrum Disorders Australia[70]
- The National Organisation for FASD (UK)[71]
- Proof Alliance[72]
- The American Psychological Association[73]

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