



A SPECTRUM OF CARE

Meet the
Unique Needs of Patients
with Fetal Alcohol Spectrum
Disorders

By Sandra J. Gonzalez, PhD, LCSW

Improving care for individuals with fetal alcohol spectrum disorders (FASDs) requires careful attention to how care is delivered in everyday moments, including intake, instructions and after-care summaries, follow-up scheduling, and conversations with caregivers. Many individuals with FASDs feel rushed, misunderstood, or judged in medical environments. Medical assistants are uniquely positioned to influence these experiences.

LIVED EXPERIENCE

When individuals and families describe living with FASDs, a fairly consistent picture emerges—one that goes beyond symptoms and diagnoses and speaks directly to how patient care is experienced. Recent qualitative work highlights that FASDs shape daily life in very concrete ways: people describe ongoing challenges with relationships, employment, housing stability, and navigating complex systems, alongside a persistent undercurrent of stigma.^{1,2} These lived accounts are consistent with quantitative findings showing significant impairments in adaptive functioning, including communication, social skills, and indepen-

dent living, even among individuals with average intellectual ability.³

FASD affects people's lives daily, influencing everything from school to independence and mental health.² Individuals themselves are often acutely aware of these difficulties. Caregivers consistently describe both the emotional weight and the practical burden of care, particularly when trying to access diagnosis and support in systems that are often fragmented or under-resourced. In fact, one recent study noted that obtaining a diagnosis can be difficult due to "lack of training, knowledge, and inadequate professional support," leaving families to navigate much of this on their own.⁴

Within health care specifically, these broader challenges show up in ways that are easy to overlook but deeply consequential. Adults with FASDs frequently describe feeling dismissed or judged, especially when symptoms are misinterpreted as noncompliance or a lack of motivation or effort. Difficulties with memory, processing speed, and executive functioning can make it hard to follow complex instructions or keep up in fast-paced clinical encounters, especially in busy, overstimulating environments.^{1,2} Thus,

navigating health care systems that require scheduling, referrals, and follow-up without support can feel overwhelming.²

Across studies and lived accounts, individuals clearly articulate what actually helps. Feeling understood is not a courtesy; it is foundational. People talk about wanting providers who slow down, communicate clearly, and meet them where they are.¹ When that happens, engagement shifts. Care is no longer something to endure but something that feels accessible. In contrast, stigma or misunderstanding reinforces the same barriers seen elsewhere: disconnection, frustration, and disengagement.^{2,3} For health care professionals, the takeaway is straightforward but crucial: respect, patience, and clear communication are not just interpersonal skills; they are clinical interventions that directly shape outcomes for individuals and families living with FASDs.

DEFINITION

FASDs is an umbrella term used to describe a continuum of conditions resulting from prenatal alcohol exposure. These effects range from mild learning and behavioral differences to profound cognitive difficul-

Life Stage	Common Presentations	Implications for Medical Assistants
Infancy and Early Childhood	Infants and toddlers with FASDs often experience significant difficulties with self-regulation, including problems with sleeping and feeding; heightened sensitivity to noise, light, or touch; high irritability; difficulty being soothed; low birth weight or failure to thrive; and frequent infections early in life.	In pediatric settings, medical assistants can support families by validating caregiver concerns, helping track developmental milestones, and reinforcing early referrals to diagnostic and support services. A calm pace and predictable handling can reduce stress for both the child and caregiver.
Preschool and Late Childhood (e.g., up to 12 years old)	As children grow, neurological differences are often misinterpreted as behavioral problems. Common concerns include intense tantrums or meltdowns, hyperactivity and impulsivity, motor and language delays, difficulty with transitions and changes in routine, and sensory overload in busy environments.	Medical assistants can help by documenting behavioral patterns, coordinating referrals, and supporting caregivers during visits. Reinforcing to the care team that repeated mistakes reflect impaired learning from experience, not defiance, can reduce stigma and inappropriate discipline.
Adolescence	Adolescence often brings increased vulnerability. Youth with FASDs may experience academic failure, particularly in math; social misunderstandings and peer conflict; difficulty understanding abstract concepts such as time, money, and risk; increased mental health challenges; and heightened susceptibility to negative peer influence.	During this stage, medical assistants play a critical role in facilitating referrals to behavioral or mental health services for screening and ongoing support, encouraging collaboration with school-based services such as individualized education plans or legally required accommodations, and involving caregivers or trusted adults to reinforce structure and safety across settings.
Adulthood	Adults with FASDs often report significant challenges in health care settings, including difficulty managing appointments and medications, misunderstanding medical instructions, sensory distress in busy clinics, poor judgment or safety awareness, and multiple co-occurring medical and mental health conditions. Adaptive functioning may worsen in adulthood, even when IQ scores fall within the typical range.	For medical assistants working with adult patients, recognizing FASD-related needs is essential for improving adherence, safety, and trust. Structured communication, written instructions, and a non-judgmental approach can significantly improve follow-through and patient experience.

ties. FASDs are solely caused by prenatal alcohol exposure. FASDs include several conditions, such as fetal alcohol syndrome (FAS), partial FAS, alcohol-related neurodevelopmental disorder, alcohol-related birth defects, and neurobehavioral disorder associated with prenatal alcohol exposure.⁵ FAS is the most involved of the diagnoses across the spectrum and is characterized by three distinct facial features. FASDs are often described as invisible disabilities because many individuals do not have physical features that are commonly associated with FAS, yet they experience substantial neurobehavioral challenges. In fast-paced health care environments, this invisibility can easily lead to incorrect assumptions about behavior and intent.⁶

FASDs affect how the brain processes information, regulates emotions, manages sensory input, and organizes behavior. A defining feature of FASDs is variability. Individuals often show uneven developmental profiles, with areas of relative strength alongside significant challenges. A patient may speak fluently and appear confident while struggling to understand instructions or remember the next steps. Another may follow information during a visit but be unable to recall it later. Because these differences are not always visible, they are frequently misunderstood.

FASDs affect individuals across the lifespan and across all backgrounds. While much of the literature has historically focused on children, increasing attention is being

paid to adolescents and adults with FASDs, many of whom encounter health care systems that are not yet designed with their neurodevelopmental needs in mind.⁴ By understanding FASDs as neurodevelopmental disabilities, medical assistants can help reduce stigma, improve care coordination, and foster more equitable health outcomes. Further, understanding how FASDs affect individuals at each stage of life⁷ can help medical assistants tailor communication, expectations, and support.

EXECUTIVE FUNCTIONING

Executive functioning deficits are among the most disabling aspects of FASDs. *Executive functioning* refers to cognitive processes that

SENSORY PROCESSING AND THE HEALTH CARE ENVIRONMENT

For many individuals with FASDs, sensory processing differences significantly affect health care experiences. Bright lighting, loud noises, crowded waiting areas, and unexpected touch can quickly overwhelm the nervous system. A blood pressure cuff tightening or a sudden change in routine may trigger anxiety or shutdown rather than cooperation. Medical assistants can reduce distress by explaining each step before it happens, maintaining a calm and steady tone, and offering simple choices that give patients a sense of control. These adjustments help regulate stress and support smoother clinical encounters.

support planning, organization, impulse control, working memory, and learning from experience. These impairments affect an individual's ability to plan and organize tasks, remember multistep instructions, manage time and appointments, learn from past consequences, and shift attention from one task to another. As a result, patients with FASDs may fully intend to follow medical recommendations yet struggle to do so consistently. This is not because of a lack of motivation or concern, but because their brains cannot reliably sequence, retain, and apply information over time.⁸

Medical assistants can play a critical role in reducing these barriers. When instructions are broken into small, concrete steps, patients are better able to process and act on information. Written or visual reminders provide external supports that compensate for memory challenges, while calm repetition of key points, delivered without judgment, reinforces understanding. Checking comprehension using teach-back methods allows medical assistants to confirm clarity and adjust communication as needed. When expectations are aligned with cognitive capacity, patients are more likely to succeed, adherence improves, and health care interactions become more effective and less frustrating for everyone involved.

SOCIAL AND EMOTIONAL DIFFERENCES

Individuals with FASDs often experience differences in social and emotional processing that extend well beyond what might be labeled as behavior problems. They may miss social cues or nonverbal signals, appear overly familiar or intrusive, and have difficulty under-

standing boundaries or recognizing danger. Many are eager to please and easily influenced, which can place them at heightened risk in social situations. These neurological differences increase vulnerability to exploitation, abuse, and legal involvement. In health care settings, they can also contribute to misunderstandings with staff when behaviors are misinterpreted as intentional or inappropriate.

Medical assistants can play an essential role in reducing harm and supporting safer interactions. Maintaining professional warmth while setting clear, explicit boundaries helps create predictable and respectful encounters. Avoiding sarcasm or abstract language reduces confusion, while allowing extra time for responses supports processing and regulation. When appropriate, involving trusted caregivers or advocates can further enhance understanding and safety. Crucially, these behaviors are neurological, not deliberate, and responding to them with clarity and respect promotes more effective and compassionate care.

CO-OCCURRING CONDITIONS AND WHOLE-BODY HEALTH

FASDs are associated with high rates of co-occurring conditions that affect both mental and physical health. Individuals with FASDs commonly experience anxiety, depression, attention-deficit/hyperactivity disorder, substance use disorders, and sleep disturbances. Many also have metabolic, cardiovascular, immune, hearing, or vision-related conditions that require ongoing monitoring and care. Despite this, health care systems too often focus narrowly

on behavioral symptoms, overlooking the multisystem health needs that shape overall functioning and quality of life.^{9,10}

Medical assistants can help promote more comprehensive and effective care by supporting routine screenings, observing and tracking patterns over time, and identifying unmet needs that may not surface during brief provider encounters. By recognizing that physical and mental health concerns are often interconnected for individuals with FASDs, medical assistants play a key role in ensuring that care addresses the whole person rather than isolated symptoms.

CREATING FASD-INFORMED HEALTH CARE ENVIRONMENTS

Health care environments can either support regulation and understanding or unintentionally increase stress for individuals with FASDs. Adults with FASDs frequently describe health care environments as difficult to navigate. Using clear, concrete language and avoiding medical jargon helps reduce cognitive overload, especially when instructions are given one step at a time. Visual supports and teach-back methods reinforce understanding without embarrassment.

Sensory considerations also matter. Minimizing noise and visual clutter when possible, offering quieter spaces, and explaining what will happen before it happens can significantly reduce anxiety. Consistent, relationship-based care—which includes greeting patients warmly, validating lived experience, acknowledging stress without judgment, and following through reliably—builds trust over time. Small, intentional adjustments like these can meaningfully reduce barriers to care and improve patient engagement.

PERSON-CENTERED AND STRENGTHS-BASED APPROACHES

Historically, FASDs have been described primarily in terms of deficits. Increasingly, research and lived experience point to the importance of recognizing strengths as a foundation for effective, respectful care. A strengths-based approach offers a more balanced perspective by recognizing abilities alongside challenges. This approach

acknowledges qualities such as creativity, empathy, honesty, perseverance, a desire for independence, and the capacity for meaningful relationships. This perspective does not minimize challenges; instead, it supports dignity, motivation, and more effective intervention. The model can be reinforced by intentionally noticing and naming patient strengths, encouraging autonomy in small but meaningful ways, supporting goals identified by the patient, and avoiding deficit-focused or labeling language. When strengths are recognized alongside support needs, health care interactions are more collaborative, and outcomes are more sustainable.

TRAUMA-INFORMED CARE

Many individuals with FASDs have experienced trauma, including within health care systems. These histories shape how health care settings are perceived and can strongly influence trust, regulation, and engagement. Trauma-informed care emphasizes safety, predictability, and respect.

Trauma-informed care begins with non-judgmental communication and an awareness that past experiences may affect current behavior. Explaining what will happen and why helps reduce anxiety, while respect for autonomy supports a sense of control. Medical assistants who remain attentive to potential triggers and validate patients' lived experiences help shift health care encounters from sources of stress into places of safety. Consistent trauma-informed practices foster trust, improve cooperation, and support more effective care over time.

NAVIGATING SYSTEMS

Health care systems are complex, particularly for individuals with executive functioning challenges, and navigating multiple appointments, referrals, and services can quickly become overwhelming. Medical assistants play a key role in helping patients with FASDs move through these systems more successfully.

Serving as a consistent point of contact (when possible) helps reduce confusion and build trust. Supporting appointment scheduling, reminders, and follow-up reduces the risk of missed care, while assistance

with referrals helps ensure connections to needed services. Coordination with behavioral health and social service providers strengthens continuity, and involving caregivers or advocates when appropriate adds an additional layer of support. When health care systems work together rather than in isolation, outcomes improve, and the burden on patients and families is reduced.

REDUCING STIGMA

Stigma remains one of the most significant barriers faced by individuals with FASDs and often begins with how behaviors are interpreted in health care settings. Stigma often enters care through language and assumptions. Labels such as “noncompliant” or “difficult” can obscure the neurological realities of FASDs and influence how future providers interpret a patient's behavior.

Medical assistants can help reduce stigma by documenting functional needs rather than judgments, using person-first language, and approaching behaviors as signals of unmet support needs. Educating team members about FASD-related challenges helps shift understanding across the care team. Every interaction shapes whether patients feel safe, supported, and willing to engage in care.

THE ESSENTIAL ROLE OF MEDICAL ASSISTANTS

Medical assistants serve as frontline advocates for individuals with FASDs, often shaping how health care is experienced from the very first interaction. Their role extends beyond clinical tasks to include observation, communication, and advocacy across systems.

By noticing patterns others may miss, setting the tone for respectful and supportive encounters, and helping patients understand and follow through with care plans, medical assistants reduce barriers that can otherwise derail care. Bridging gaps between providers and services while consistently upholding dignity in everyday interactions helps transform health care from another obstacle into a source of stability and support. When medical assistants adapt communication, environments, and expectations accordingly, the impact reaches far beyond the exam-

ination room and contributes meaningfully to health equity for an often-overlooked population. ♦

The CE test for this article can be found on page 27.



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