

What People With FASDs and their Families Want Healthcare Professionals To Know!

Fetal alcohol spectrum disorders (FASDs) are a group of lifelong neurodevelopmental conditions that can lead to challenges in the healthcare system. The best patient outcomes occur when healthcare workers understand the individual's developmental needs, listen to living experience, communicate clearly, and provide ongoing interdisciplinary support—especially during the transition to adulthood.

Understanding FASD as a Lifelong, Whole-Body Condition

- FASDs are a continuum of lifelong diagnoses that affect the whole body, including social, emotional, or cognitive functioning. FASDs are seen in adults, not just in pediatrics.
- You can't tell if someone has an FASD by looking at them. Only 10% of people with FASDs display the facial features associated with fetal alcohol syndrome.
- Individuals often have complex, co-occurring medical conditions. Be aware that individuals with FASD may also experience conditions such as ADHD, growth deficiencies, mental health conditions, joint issues, heart conditions, vision and hearing concerns, speech and language delays, sleep difficulties, & feeding and food-related challenges.

Practical Tips

	Many behaviors associated with FASD are often misunderstood as intentional “misbehavior” or defiance. However, these behaviors are frequently symptoms of brain-based differences caused by prenatal alcohol exposure. View behavior as communication, unmet needs, and/or skill deficits.	Success often depends on adapting environments and supports rather than expecting the individual to “try harder.”	
	Avoid overwhelming individuals with too much information; break recommendations into clear, step-by-step instructions.	Focus on the person's strengths, goals, interests, and living experience—not just the diagnosis.	
	Use simple, concrete language and check for understanding. Provide written summaries after appointments and reminders to reach out with questions.	Speak directly to the individual first and involve families and caregivers as partners in care.	
	Schedule longer appointments when possible and allow extra time for processing and questions.	Trust and value the knowledge of individuals, parents, and caregivers regarding needs, challenges, and effective supports.	
	Base expectations and support plans on developmental stage rather than chronological age (“stage, not age”).	Connect individuals and families with relevant resources and community supports.	
		Strive to reduce misunderstanding, stigmatization, and underestimation of individuals with an FASD.	

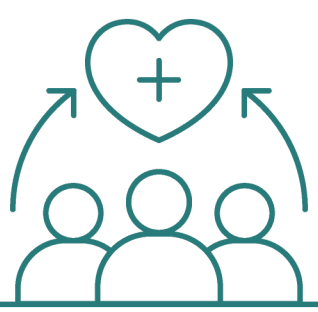


Make Note! The Transition to Adulthood

- The transition to adulthood is a particularly vulnerable and often under-supported period for individuals with an FASD. Early planning that prioritizes supportive interdependence over independence can improve outcomes.
- Around age 18, supports and expectations change abruptly as individuals move from structured youth systems to less structured adult environments and healthcare services.
- A mismatch between adult expectations and developmental abilities can lead to increased stress, functional difficulties, and safety concerns.

Effective Care Requires:

- ✓ FASD-informed practice and neurodiversity awareness
- ✓ Interdisciplinary collaboration
- ✓ Inclusion of all perspectives
- ✓ Family and caregiver involvement
- ✓ Respect for living experience



“People with an FASD have often spent their whole lives being misunderstood, underestimated, and under-supported by systems that weren't built for them or by them. Healthcare doesn't have to be another one of those systems. You have the power to make a difference in the lives of those with FASD.”
- Person with FASD