

30 Things We Need for those with FASD with **LOVE** from the 5,600 Caregiver Voices

1. Yes, **FASD is Real**. Like Autism, FASD needs to be recognized as a disability and have its own umbrella to receive services.

2. There needs to be **more understanding** that FASD is not just FAS with the face—9 out of 10 individuals with FASD will not have outward signs. Research often only studies FAS. The majority with FASD will not have an intellectual disability, but will still have organic brain damage or internal damage. IQ often becomes a barrier to get services.

3. We need **FASD specific disability services**. FASD is a complex spectrum disorder. Research has shown that a person with FASD could have any, or a combination of 428 secondary diagnoses. The current categories of disability are not an adequate fit for those with FASD.

4. A child/adult with an FASD needs to get the **same realm of insurance, services and system benefit** as someone diagnosed with Autism or an intellectual disability.

5. We need a **road map of FASD**, including diagnostics, early intervention, treatment, and interventions. We need a unified, cohesive treatment team with individuals and caregivers being respected partners on these teams. We need support systems for those with FASD.

6. With FASD, we need to think **Developmental versus Chronological**. Age is not relevant when dealing with this disability due to the complex damage alcohol causes. Behavior is language. We need to look at what they are telling us to save their self-esteems to prevent the trauma and reactivity compounded by school failure. We need proactive thinking instead of reactivity.



7. We need to **know the areas affected** in our child and their struggles: social skills, auditory processing, visual processing, sensory integration disorders. Interventions used in the Autism may benefit many.

8. Persons with FASD need an **early and timely diagnosis**. They need comprehensive and up to date evidence-based access to FASD Diagnostic Clinics in every state. Families are asking for Care Clinics that will diagnose and help manage consistent care and supports for the children and families throughout a person's lifetime.

9. We need a **National strategy to help those with FASD** and change the paradigm that those with FASD are hopeless. Instead of blaming the victims, we need to empower them and give them HOPE.

10. Families want **Health Professionals to be trained** with up to date information and to have available information on how to help the children and the adults.

11. Health care providers need to have **the tools and screening to identify** those who may be affected with FASD and where to send them for a diagnostic evaluation and support.

12. We need to create **FASD Developmental Medical Care Centers** with an evidence-based model approach to help guide caregivers through childhood, transition and adult services.

13. Children diagnosed under the FASD umbrella should have **a qualification category for an IEP like Autism** to allow more proactive support and a more comprehensive support network that is understanding.

14. Persons with FASD need more **supports throughout their whole lifetime**. Failure to do so increases the likelihood of secondary mental health disorders, homelessness, 2nd generation FASD, involvement in the justice system and the cycle of addiction.
15. The current qualifiers do not adequately address the unique differences for those who have an FASD. Every child with FASD needs an **early autism evaluation** realizing that many of those with FASD may also have an Autism diagnosis.
16. For those who are diagnosed with Autism, we need to **ask the hard question**. Did you drink the month you found out you were pregnant or after?
17. Children and teens in foster care be **automatically screened for FASD**, (literature suggests up to 70% or more are prenatally exposed). Provide FASD parenting education to all foster caregivers.
18. We need to **see behavior as language**. The action is telling us that the individual is struggling.
19. Many of our kids struggle with reading and learning. For children who have FASD **assess for vision** services through schools. Research states that the eyes are affected by alcohol. We need to look at their lenses AND how they use their eyes. Look for neurological vision issues. Many are secondarily diagnosed with dyslexia.
20. We need **schools to be open** to meeting our kids' needs when they are developmentally and emotionally ready.
21. Our **teachers' need training** in recognizing and educating those with FASDs. New research states 1 in 20 children may have FASD's. We need to equip educators with the knowledge and tools to teach these children successfully.
22. We need to **think pro-actively** versus reactively and support trauma-based learning to stop school failure. The development and creation of evidence-based strategies already exists for persons with FASD we need to use them.
23. We need a **National model of training** that encompasses all the disciplines that work with children/adults and families with FASD. Focus on more than prevention and research, putting an emphasis on how to support persons affected.
24. We need **systems training** on FASD. Child Welfare, Educational, Mental Health, Disability Support Systems, and Justice Systems.
25. We need **support for the adults** living with FASD. Research states 80% of those with FASD's will need help navigating and living their lives.
26. We need **person-centered living** with natural community supports to help them meet their needs.
27. We need **Family and Caregiver Support** to help those caring for those with FASD. This 24/7 day-to-day job for caregivers is taxing, and secondary mental health diagnoses and stress on families is REAL and has detrimental consequences.
28. Caregivers need **RESPIRE**. Supports, camps, and retreats are a real need. We need opportunities for those affected to come together to play, learn and normalize FASD. Funding is needed for camps for kids and adults with FASD, and caregiver retreats.
29. We need to **create opportunities and supports** to improve the level of functioning, health and well being of those affected by prenatal alcohol exposures.
30. We need to look at persons with FASD with **different lenses** and realize their behaviors are unmet needs. Then we can change outcomes.



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