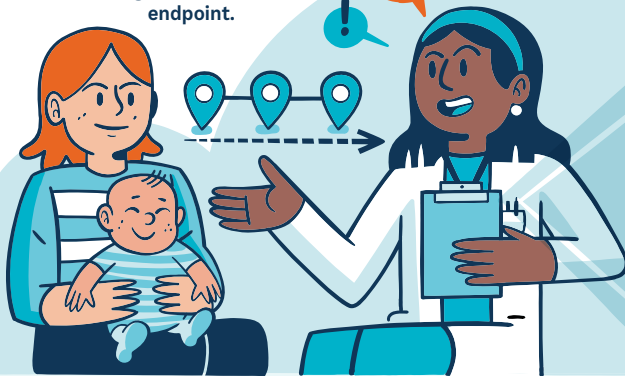


PRIMARY CARE MANAGEMENT ACROSS THE LIFESPAN

AFTER A FETAL ALCOHOL SPECTRUM DISORDER (FASD) DIAGNOSIS

DIAGNOSIS

An FASD diagnosis begins lifelong care. It is not the endpoint.



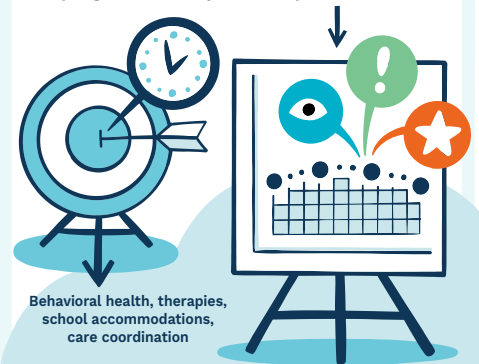
FUNCTIONAL ASSESSMENT

Assess how FASDs affect daily functioning, not the diagnosis alone.



START SERVICES EARLY

Initiate targeted support early, monitor progress and adjust care plan over time.



Behavioral health, therapies, school accommodations, care coordination

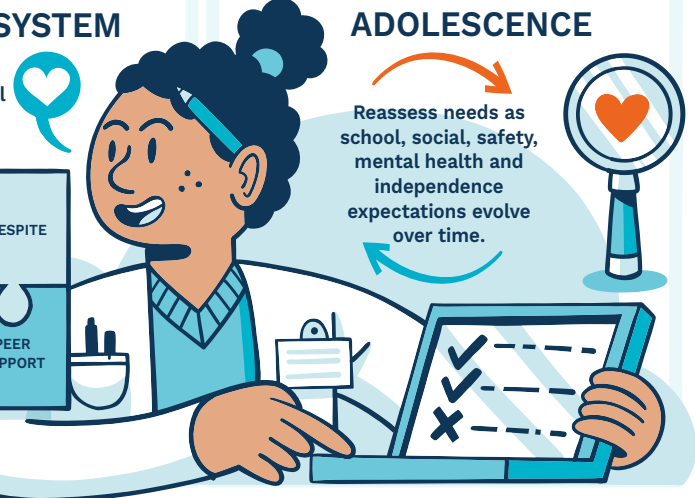
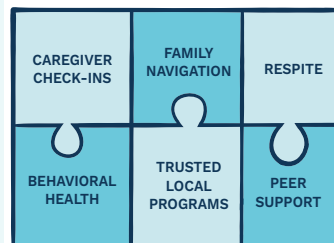
PRIMARY CARE CLINICAL HUB

Primary care connects referrals, care plans, accommodations, follow up and communication across the care team.



CAREGIVER SYSTEM

Support caregivers and connect families to practical community resources.



ADOLESCENCE

Reassess needs as school, social, safety, mental health and independence expectations evolve over time.

ADULT RECORDS TRANSFER

Transfer functional history, successful strategies and relevant medical records, not just the diagnosis.



ADULTHOOD

Adults with FASDs benefit from ongoing primary care, practical assistance and connection to community support.

HEALTH CARE
EMPLOYMENT
TRANSPORTATION
EDUCATION
SAFETY
BENEFITS
DAILY ROUTINES

DECISION-MAKING

Promote autonomy through supported decision-making and the least restrictive options.



After an FASD diagnosis, primary care shifts from identification to long-term management. Family physicians should translate diagnostic findings into a practical care plan throughout childhood, adolescence and adulthood. FASD is lifelong, and the needs of the individual often change over time. The primary care provider can coordinate clinical care, behavioral health, school accommodations, community resources and transition planning.¹⁻⁴

1. START WITH FUNCTIONAL ASSESSMENT

Build from the diagnosis to clarify how FASDs affect daily function. Ask about learning, attention, executive function, emotional regulation, communication, adaptive skills, safety and caregiver priorities. Screen for co-occurring physical, developmental, behavioral and medical conditions. Treating these conditions may improve outcomes and functioning.⁵⁻⁷

Screen for⁸: ADHD, anxiety, sleep concerns, learning or language disorders or delays, sensory processing differences, vision or hearing concerns, seizures, feeding or growth concerns, gastrointestinal symptoms, musculoskeletal abnormalities, renal abnormalities, cardiac abnormalities and chronic conditions

2. COMMUNICATE CLEARLY AND WITHOUT STIGMA

Use language that is accurate, direct and non-stigmatizing. Frame FASDs as a brain-based condition that requires structure and realistic expectations alongside consistent care rather than a behavior problem or a parenting failure.^{9,10}

Suggested language: “This diagnosis helps us understand how your child learns, regulates emotions and manages daily expectations. It gives us a starting point to choose strategies that fit how your child’s brain works.”

3. START SERVICES AND CARE COORDINATION EARLY

Prioritize referrals and care that address the family’s most urgent functional concerns and schedule follow-up visits to confirm access and benefits by:

- Prioritizing behavioral health, parent/caregiver training, indicated therapies and school accommodations (i.e., Section 504 or individualized education program [IEP]).^{7,11-13}
 - Section 504: Students who meet the disability requirements “under Section 504 are entitled to receive regular or special education and related aids and services that are designed to meet their individual educational needs as adequately as the needs of students without disabilities are met.”¹² Physicians contribute to this process through diagnoses, recommendations for medication and schedules, and notes about physical or health-related needs.

- Individualized education program: For public school children with disabilities who qualify under the Individuals with Disabilities Education Act (IDEA), an IEP is a legally binding document that outlines specific goals, services and accommodations tailored to the student’s individual needs to help them make meaningful progress in school. Physicians contribute to this process through diagnosis, documentation of functional concerns, medication needs, related health needs and recommendations that may inform school-based supports.
- Considering medication management for targeted symptoms or co-occurring conditions when clinically appropriate.^{7,14}

4. MAKE PRIMARY CARE THE CLINICAL HUB

Primary care is often the place where various recommendations become a cohesive care plan. Family physicians can help caregivers close referral loops, document effective strategies, revisit the school plan and address behavioral and family needs by²⁻⁴:

- Identifying priority needs and documenting a shared care plan.
- Coordinating with behavioral health specialists, medical specialists, school officials and community partners.
- Tracking whether referrals were completed and the care plan still fits the current needs.

5. SUPPORT CAREGIVERS AND CONNECT FAMILIES TO COMMUNITY SUPPORTS

Caregivers are often the consistent people engaged in attending medical visits, school meetings, behavioral health visits and solving issues for patients with an FASD. Supporting caregivers is also part of the FASD treatment plan. Family physicians can ask caregivers about their strain, sleep, access to respite, and ability to manage patient behaviors and family needs. Transportation barriers, school advocacy needs, isolation, financial strain and difficulty finding FASD-informed services are common issues for caregivers.^{2,15-17}

Family physicians can offer a caregiver check-in by:

- Empathizing about caregiver fatigue and asking what would make daily care more manageable.
- Framing expectations about developmental and adaptive functioning, not chronological age alone.
- Connecting families with practical supports, such as care coordination, family navigation, peer support, respite, behavioral health support, disability service organizations and trusted local programs.
- Revisiting community supports as the patient moves through childhood, adolescence and adulthood. Needs may shift from early intervention and school services to care coordination, vocational rehabilitation, transportation planning, benefits counseling and supported living or adult disability services.

- Encouraging caregivers to maintain their own medical care and to seek behavioral health support before stress or burnout affects functioning.

Physician prompt: “Who helps your family manage day-to-day needs?” A short question such as this directed at a caregiver can identify trusted support, unmet needs and community resources that should be reflected in the care plan.

6. ADOLESCENCE: REASSESS, ADAPT AND PREPARE

Adolescence often exposes new gaps between what the patient is expected to manage and what they can reliably do without support. This transitional stage brings about changing school demands, emerging autonomy, social complexity and behavioral health needs.

For teens with FASDs, executive functioning, emotional regulation, adaptive skills and risk recognition may not align with chronological age, making proactive planning essential by^{3,4,15,17-21}.

- Ensuring preventive health care is adequately addressed (e.g., immunizations).
- Reassessing mental health, sleep, behavior, substance use risk, sexuality, safety concerns and family stress.
- Updating supports to match developmental, school and vocational expectations.
- Building youth participation in care while maintaining caregiver strategies.
- Continuing to coordinate with schools around transition goals, IEP planning, vocational support and life skills.
- Beginning a structured transition plan before services change with age.

7. PEDIATRIC TO ADULT CARE: A HIGH-RISK GAP

The transition from pediatric to adult care systems is a predictable risk point for patients with FASDs.⁴ School-based services, specialty supports and care coordination may change or end. A concise medical and functional summary can help preserve the lessons learned by the family and pediatric care teams. Family physicians are uniquely positioned to reduce care gaps as patients transition from pediatric to adult systems.

As youth with FASDs approach adulthood, caregivers may need guidance on health care decision-making, consent and privacy, legal rights, safety, finances, daily living and the appropriate level of caregiver support or involvement. These conversations should begin well before the transfer to adult care, so the plan can be revisited as needs, capacity and available supports change. Care teams can assist this transition by^{4,19-21}.

- Identifying the adult care providers and clinicians early.
- Preparing a concise medical and functional summary, including diagnosis, co-occurring conditions, medications,

effective strategies, accommodations, communication needs and caregiver roles.

- Ensuring continuity of behavioral health therapy and medication management where possible.
- Discussing consent, privacy, release-of-information forms, supported decision-making and care-partner roles before the age of 18.
- Revisiting transition readiness at multiple visits rather than treating transfer as a single event.

8. ADULTHOOD: SUSTAIN FUNCTION, PARTICIPATION AND SAFETY

In adulthood, clinical focus shifts toward sustaining health, function, safety and participation. Adults with FASDs continue to benefit from primary care, behavioral health, medication management, practical assistance and community support tailored to their functional needs.²²

9. SUPPORTED DECISION-MAKING AND ADULT HEALTH CARE PLANNING

Supported decision-making is an approach that allows individuals to retain decision-making authority while receiving assistance from trusted supporters. Supporters may help the person understand information, compare options, communicate preferences, organize tasks and follow through with decisions, while the individual remains the decision-maker whenever possible. Health care providers can assist with supported decision-making by asking some of the following questions^{17,23-25}:

- **Health care:** Who will schedule appointments, help the patient understand treatment plans, attend visits and/or assist with HIPAA releases?
- **Medications:** Can the patient manage refills, dosing, side effects and pharmacy communication independently?
- **Finances and benefits:** Does the patient need help with banking, budgeting, insurance, disability benefits or need a representative payee arrangement?
- **Housing and daily living:** What level of support is needed for safety, meals, transportation, home routines and crisis planning?
- **Education and employment:** What accommodations, vocational support and job coaching would improve success?
- **Safety:** How will risks related to exploitation, coercion, unsafe relationships, substance use and legal involvement be addressed?

Supported decision-making exists on a continuum. Options may include informal family support, supported decision-making agreements, release-of-information forms, health care proxies, durable powers of attorney, representative payee arrangements or guardianship when necessary.^{23,24} The least restrictive approach that promotes safety, dignity, communication and participation should generally be considered first, with legal guidance as needed.

Closing message: Diagnosis is the starting point. Since FASD is a spectrum, each patient's strengths, challenges and support needs will differ. Primary care helps patients and families turn the diagnosis into coordinated services, practical strategies and continuity across the lifespan.²⁶

REFERENCES

1. American Academy of Pediatrics. Fetal alcohol spectrum disorders. Accessed July 16, 2026. www.aap.org/en/patient-care/fetal-alcohol-spectrum-disorders/
2. American Academy of Pediatrics. Case management for fetal alcohol spectrum disorders. Accessed July 1, 2026. www.aap.org/en/patient-care/fetal-alcohol-spectrum-disorders/practice-management/case-management-for-fetal-alcohol-spectrum-disorders/
3. Got Transition. Six core elements of health care transition. Accessed July 16, 2026. www.gottransition.org/six-core-elements/
4. White PH, Cooley WC, Transitions Clinical Report Authoring Group, American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2018;142(5):e20182587.
5. Popova S, Lange S, Shield K, et al. Comorbidity of fetal alcohol spectrum disorder: a systematic review and meta-analysis. *Lancet*. 2016;387(10022):978-987.
6. Vanderpeet C, Akison L, Moritz K, Hayes N, Reid N. Beyond the brain: the physical health and whole-body impact of fetal alcohol spectrum disorders. *Alcohol Res*. 2025;45(1):05.
7. Breuer L, Greenmyer JR, Wilson T. Clinical diagnosis and management of fetal alcohol spectrum disorder and sensory processing disorder in children. *Children (Basel)*. 2024;11(1):108.
8. Gill K. Fetal alcohol spectrum disorders (FASDs). MedicalNewsToday. January 26, 2024. Accessed July 16, 2026. www.medicalnewstoday.com/articles/fetal-alcohol-spectrum-disorders
9. Glass L, Mattson SN. Fetal alcohol spectrum disorders: a case study. *J Pediatr Neuropsychol*. 2017; 3(2):114-135.
10. Proof Alliance. Practical guide for designing and implementing fetal alcohol spectrum disorder diagnostic and clinical care practices. 2025. Accessed July 16, 2026. www.proofalliance.org/wp-content/uploads/2025/02/FASD-Diagnostic-Guidelines-A-Comprehensive-Clinical-Guide-1.pdf
11. American Academy of Pediatrics. Behavioral interventions in fetal alcohol spectrum disorders. Accessed July 16, 2026. www.aap.org/en/patient-care/fetal-alcohol-spectrum-disorders/health-supervision/behavioral-interventions-in-fetal-alcohol-spectrum-disorders/
12. U.S. Department of Education. Office for Civil Rights. Parent and educator resource guide to Section 504 in public elementary and secondary schools. December 2016. Accessed July 16, 2026. www.ed.gov/sites/ed/files/about/offices/list/ocr/docs/504-resource-guide-201612.pdf
13. U.S. Department of Education. Office of Special Education and Rehabilitative Services. IDEA Regulations: Individualized Education Program (IEP). Accessed July 16, 2026. https://sites.ed.gov/idea/files/IEP_10-4-06.pdf
14. Wozniak JR, Riley EP, Charness ME. Diagnosis, epidemiology, assessment, pathophysiology, and management of fetal alcohol spectrum disorders. *Lancet Neurol*. 2019;18(8):760-770.
15. CanFASD. Life transitions for people with FASD: CARE Study update. August 14, 2024. Accessed July 16, 2026. <https://canfasd.ca/2024/08/14/life-transitions-for-people-with-fasd-care-study-update/>
16. Kautz C, Parr J, Petrenko CLM. Self-care in caregivers of children with FASD: how do caregivers care for themselves, and what are the benefits and obstacles for doing so? *Res Dev Disabil*. 2020;99:103578.
17. Gibson AC, Velhagen JM, Jaffe T, et al. Overcoming barriers to care for individuals with fetal alcohol spectrum disorder: challenges and solutions in New Mexico and beyond. *Front Pediatr*. 2025;13:1603765
18. FASD United. Family Navigator. Transition to adulthood. Accessed July 16, 2026. <https://fasdunited.org/wp-content/uploads/2024/02/Transition-age-fact-sheet-.pdf>
19. FASD Network. FASD and transitioning to adulthood – a guide for parents and carers. Accessed July 16, 2026. www.fasdnetwork.org/uploads/9/5/1/1/9511748/fasd_fact_sheet_8_-_transitioning_to_adulthood__2025.pdf
20. WRAP2FASD. Fetal alcohol spectrum disorder and transitions during adolescence. Accessed July 16, 2026. https://wrap2fasd.org/wp-content/uploads/2025/06/Transitions-Factsheet_V2.pdf
21. Flannigan K, Coons-Harding KD, Anderson T, et al. A systematic review of interventions to improve mental health and substance use outcomes for individuals with prenatal alcohol exposure and fetal alcohol spectrum disorder. *Alcohol Clin Exp Res*. 2020;44(12):2401-2430.
22. Substance Abuse and Mental Health Services Administration. *Addressing fetal alcohol spectrum disorders (FASD)*. Treatment Improvement Protocol (TIP) Series, No. 58. Center for Substance Abuse Prevention. Rockville, MD; 2014.
23. National Disability Rights Network. Supported decision making and health care. April 25, 2019. Accessed July 16, 2026. www.ndrn.org/resource/supported-decision-making-and-health-care/
24. Center for Public Representation. SDM and health care decisions. Accessed July 16, 2026. <https://supporteddecisions.org/getting-started-with-supported-decision-making/sdm-and-health-care-decisions/>
25. Casey H, Trayer Á, Desmond D, et al. Experiences and perceptions of everyday decision-making in the lives of adults with intellectual disabilities, their care partners and direct care support workers. *J Intellect Disabil*. 2025;29(3):683-705.
26. Turchi RM, Smith VC, Committee on Substance Use and Prevention, Council on Children with Disabilities. *Pediatrics*. 2018;142(4):e20182333.