ADOPTING AND FOSTERING CHILDREN WITH FETAL ALCOHOL SPECTRUM DISORDERS

Parenting has been called the toughest but most fulfilling job in the world. Parenting children with special needs, such as fetal alcohol spectrum disorders (FASD), brings its own set of challenges.

Many parents of children with an FASD are adoptive or foster parents. Some knew about FASD when they welcomed their children into their family, while others did not. In any case, information is the key to success in raising children with an FASD.

Learning about FASD can help parents understand how their children are affected, which parenting strategies work best, and how to get services and support. For people who want to adopt or foster a child with an FASD, knowing the facts can help them make an informed decision.

WHAT IS FASD?

"FASD" is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications. The term FASD is not intended for use as a clinical diagnosis. It refers to conditions such as fetal alcohol syndrome (FAS), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD). In the United States, FASD occurs in about 10 per 1,000 live births, or about 40,000 babies per year.¹

There is little information available about FASD and adoption or foster care. One study of children in foster care in Washington State revealed a rate of FAS 10 to 15 times higher than in the general population, suggesting that children in foster care are more likely to have an FASD.² Estimates for international adoptions vary by country. In Russian orphanages, the rate of FAS alone has been estimated at 1 to 10 per 100.³

MEETING THE CHALLENGES ASSOCIATED WITH FASD

Brain damage and physical defects are the primary disabilities associated with FASD. Lifelong behavioral or cognitive problems may include:

- Mental retardation
- Learning disabilities
- Hyperactivity

- Attention deficits
- Problems with impulse control, social skills, language, and memory

These challenges can lead to other problems called secondary disabilities, which may include:

- Disrupted school experience
- Alcohol and substance abuse
- Mental illness
- Dependent living
- Problems with employment
- Inappropriate sexual behavior
- Involvement in the criminal or juvenile justice system
- Confinement (prison or inpatient treatment for mental health or substance abuse problems)⁴

A child with an FASD is likely to need services throughout his or her life and may never be able to live independently. The lifetime cost for one child with FAS can be \$2 million.⁵

Despite their challenges, children with an FASD have a number of strengths. For example, they tend to be caring, creative, determined, and eager to please. They also respond well to structure, consistency, concrete communication, and close supervision. With a supportive home, an early diagnosis, and appropriate services, many children with an FASD can avoid secondary disabilities and reach their full potential.



GATHERING INFORMATION

Many children who have an FASD lack an accurate diagnosis and their problems may not be clear. Prospective parents may request a copy of a child's complete medical and family history. However, because records may not tell the whole story, they may also ask specific questions about:

- Possible prenatal exposure to alcohol or drugs
- The physical and mental health of the mother and any siblings
- The developmental history of the child, including possible delays
- Independent evaluations from a physician

Most States require adoption and foster care agencies to share information with prospective parents about the health and social history of the child and birth parents. Some States require more information sharing than others, but few specifically address alcohol.⁷ Full investigation and disclosure is best for everyone so that placements are successful, parents are prepared, and children get the help they need.

CONCLUSION

Parenting offers many rewards, despite its hurdles. Those who choose to become a parent or caregiver to a child with an FASD experience great joy along with the challenges. The child can benefit from a stable, loving home with parents and caregivers who understand his or her needs. Ultimately, adoptive and foster parents can change the outlook for individuals with an FASD, one day at a time.

Tips for Adopting or Fostering Children Prenatally Exposed to Alcohol or Other Drugs

- 1. Work with informed professionals in quality adoption agencies.
- 2. Explore your feelings about alcohol and drug abuse, particularly among pregnant women.
- 3. Discuss the child's background with your social worker so that you have a realistic picture of the birth parents' substance use and related lifestyle.
- 4. Ask for written summaries of the child's diagnoses, medical complications, treatment services, and necessary followup care.
- 5. Ask for information on services and resources to meet the child's needs, including eligibility for adoption subsidies and Medicaid.
- 6. Find out how to reduce the impact of the child's biological risks by providing a nurturing, responsive, and healthy caregiving environment.
- 7. Recognize that you must be prepared for and able to tolerate the uncertainties that are part of adopting a child prenatally exposed to drugs or alcohol.
- 8. Resist negative stereotypes of children prenatally exposed to drugs or alcohol, which ignore the individuality of each child and the role of a healthy environment.
- 9. Recognize the importance of timely identification of problems and early intervention.

Adapted from Edelstein, S. 1995. *Children With Prenatal Alcohol and/or Other Drug Exposure: Weighing the Risks of Adoption.* Washington, DC: CWLA Press.

REFERENCES

- 1. May, P.A., and Gossage, J.P. 2001. Estimating the prevalence of fetal alcohol syndrome: A summary. Alcohol Research & Health 25(3):159–167.
- 2. Astley SJ; Stachowiak J; Clarren SK; Clausen C. Application of the fetal alcohol syndrome facial photographic screening tool in a foster care population. *Journal of Pediatrics* 141(5): 712-717, 2002.
- Center for Adoption Medicine. University of Washington. 2005. http://www.adoptmed.org/display/ShowJournal?moduleId=171564&categoryId=13631
- 4. Streissguth, A., and Kanter, J., eds. 1997. The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities. Seattle: University of Washington Press.
- 5. Lupton, C., Burd, L., Harwood R. Cost of fetal alcohol spectrum disorders. Am J Med Genet 127C(676): 42-50, 2004.
- 6. Teaching Students With Fetal Alcohol Syndrome/Effects: A Resource Guide for Teachers. Ministry of Education, Government of British Columbia, 1996. http://www.bced.gov.bc.ca/specialed/fas
- 7. U.S. Department of Health and Human Services. Administration for Children and Families. National Adoption Information Clearinghouse. 2003 Adoption State Statutes Series Statutes-at-a-Glance: Collection of Family Information About Adopted Persons, Birth Parents, and Adoptive Parents. http://naic.acf.hhs.gov/general/legal/statutes/collection.pdf

Stop and think. If you're pregnant, don't drink. For more information, visit **fasdcenter.samhsa.gov** or call 866-STOPFAS. www.stopalcoholabuse.gov



SAMHSA
Fetal Alcohol Spectrum Disorders
Center for Excellence