

## PREVENTION WORKS!

### *CHILDREN LIVING IN STRESSFUL ENVIRONMENTS: A RESOURCE KIT*

#### *VI.b. Children With Fetal Alcohol Spectrum Disorders (FASD)*

##### **Discussion**

*“Of all the substances of abuse (including cocaine, heroin, and marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus.”*

Institute of Medicine (IOM) Fetal Alcohol Syndrome Report to Congress, 1996

When a woman who is pregnant consumes alcohol, the alcohol crosses the placenta into the fetal blood stream and may damage developing tissue and organs. Such damage may result in mental retardation, social and emotional problems, learning disabilities, and other problems. Diagnosing FASD is difficult, calling for a combination of physical, mental, and psychological testing and a team of professionals representing several disciplines.

Although not all children born to women who drink during pregnancy have FASD, no safe level of alcohol consumption during pregnancy has been identified, nor have any types of alcoholic beverages (e.g., wine vs. distilled spirits) been found to be less dangerous to the fetus. However, FASD is 100 percent preventable when women who are pregnant or planning to become pregnant avoid alcohol completely.<sup>1</sup>

“Fetal alcohol spectrum disorders (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 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).”<sup>2</sup>

<sup>1</sup> FASD Center for Excellence. (May 2004). *The language of fetal alcohol spectrum disorders*. Rockville, MD: SAMHSA. Retrieved April 21, 2008, from [www.fasdcenter.samhsa.gov/documents/WYNKLanguageFASD2.pdf](http://www.fasdcenter.samhsa.gov/documents/WYNKLanguageFASD2.pdf).

<sup>2</sup> FASD Center for Excellence. (May 2004). *The language of fetal alcohol spectrum disorders*. Rockville, MD: SAMHSA. Retrieved April 21, 2008, from [www.fasdcenter.samhsa.gov/documents/WYNKLanguageFASD2.pdf](http://www.fasdcenter.samhsa.gov/documents/WYNKLanguageFASD2.pdf).

### ***Fetal Alcohol Syndrome (FAS)***

FAS is a pattern of neurologic, behavioral, and cognitive deficits. These defects can interfere with growth, learning, and socialization. Indicators of possible FAS include:

- Facial abnormalities (e.g., small eye openings, indistinct/flat philtrum, thin upper lip);
- Low birth weight; growth deficiencies;
- Brain damage; small skull at birth, structural defects, impaired fine motor skills, poor eye-hand coordination, and tremors; and
- Maternal drinking during pregnancy.

Behavioral or cognitive problems associated with FAS may include mental retardation; learning disabilities; attention deficits; hyperactivity; poor impulse control; and social, language, and memory deficits. Partial FAS describes persons with confirmed alcohol exposure, facial anomalies, and one other group of symptoms (e.g., growth retardation, central nervous system defects, or cognitive deficits).<sup>3</sup>

### ***Fetal Alcohol Effects (FAE)***

FAE describes children with prenatal alcohol exposure who do not have all the symptoms of FAS. Many have growth deficiencies, behavior problems, cognitive deficits, and other symptoms. However, they do not have the facial features of FAS. Although the term FAE is still used, the IOM has coined more specific terms. These include alcohol-related neurodevelopmental disorder (ARND) and alcohol-related birth defects (ARBD). Children with ARND have central nervous system deficits but not all the physical features of FAS. Their problems may include sleep disturbances, attention deficits, poor visual focus, increased activity, delayed speech, and learning disabilities. Children with ARBD may have heart, eye, ear, kidney, or skeletal abnormalities, such as holes in their hearts, underdeveloped kidneys, or fused bones.<sup>4</sup>

As a means of clarifying these terms and the differences between them, the IOM developed diagnostic criteria for FAS and other spectrum alcohol-related disorders:<sup>5</sup>

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<sup>3</sup> FASD Center for Excellence. (May 2004). *The language of fetal alcohol spectrum disorders*. Rockville, MD: SAMHSA. Retrieved April 21, 2008, from [www.fasdcenter.samhsa.gov/documents/WYNKLanguageFASD2.pdf](http://www.fasdcenter.samhsa.gov/documents/WYNKLanguageFASD2.pdf).

<sup>4</sup> FASD Center for Excellence. (May 2004). *The language of fetal alcohol spectrum disorders*. Rockville, MD: SAMHSA. Retrieved April 21, 2008, from [www.fasdcenter.samhsa.gov/documents/WYNKLanguageFASD2.pdf](http://www.fasdcenter.samhsa.gov/documents/WYNKLanguageFASD2.pdf).

<sup>5</sup> Warren, K. R., and Foudin, L. L. (2001) Alcohol-related birth defects—The past, present and future. *Alcohol Research and Health*, 25(3), 153-158. Retrieved January 16, 2008, from <http://pubs.niaaa.nih.gov/publications/arh25-3/153-158.pdf>.

## **IOM-Recommended Diagnostic Criteria for FAS and Alcohol-Related Effects**

### **Category 1. FAS With Confirmed Maternal Alcohol Exposure**

1. Confirmed maternal alcohol exposure \*
2. Characteristic pattern of facial anomalies, including short palpebral fissures, and abnormalities of the premaxillary zone (e.g., flat upper lip, flat tened philtrum, flat midface)
3. Growth retardation, such as low birth weight, lack of weight gain over time, disproportional low weight to height
4. Neurodevelopmental abnormalities of the CNS, such as small head size at birth; structural brain abnormalities with age-appropriate neurological hard or soft signs (e.g., impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor eye-hand coordination)

### **Category 2. FAS Without Confirmed Maternal Alcohol Exposure**

*Characteristics 2-4 as in Category 1*

### **Category 3. Partial FAS With Confirmed Maternal Alcohol Exposure**

1. Confirmed maternal alcohol exposure \*
2. Some components of the FAS facial pattern *either 3, 4, or 5 below*:
3. Growth retardation as in Category 1
4. CNS neurodevelopmental abnormalities as in Category 1
5. Complex pattern of behavioral or cognitive abnormalities inconsistent with developmental level and unexplained by genetic background or environmental conditions (e.g., learning difficulties; deficits in school performance; poor impulse control; problems in social perception; language deficits; poor capacity for abstraction; specific deficits in mathematical skills; and problems in memory, attention, or judgment)

### **Category 4. Alcohol-Related Birth Defects (ARBD)**

1. Confirmed maternal alcohol exposure \*
2. One or more congenital defects, including malformations and dysplasias of the heart, bone, kidney, vision, or hearing systems

### **Category 5. Alcohol-Related Neurodevelopmental Disorder (ARND)**

1. Confirmed maternal alcohol exposure \*
2. CNS neurodevelopmental abnormalities as in Category 1 *and/ or*
3. Complex pattern of behavioral or cognitive deficits as in Category 3

\* Maternal alcohol exposure is defined as a pattern of excessive alcohol intake characterized by substantial, regular intake or by heavy episodic (i.e., binge) drinking. Evidence of this pattern may include signs of alcohol dependence.

CNS = central nervous system; FAS = fetal alcohol syndrome; IOM = Institute of Medicine.

SOURCE: Stratton et al. 1996 a.

The original IOM criteria are still referenced in publications about FASD. But a more recent criteria outline, with accompanying text, can be found on page 20 of the Centers for Disease Control and Prevention's (CDC's) National Center on Birth Defects and Developmental

Disabilities' July 2004 *Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis*,<sup>6</sup> which was designed for medical and allied health students and practitioners and medical accrediting boards.

Children with FASD are at very high risk for trouble in school, trouble with the law, alcohol and drug abuse, and mental health disorders.<sup>7</sup> However, CDC reports that interventions currently in use for children with FAS/ARND tend to be “non-specific, unsystematic, and/or lack scientific evaluation or validation.” In 2006, CDC said that they were collaborating with some of their grantees to “identify, develop, and evaluate effective strategies for intervening with children with FAS/ARND and their families.”<sup>8</sup>

Meanwhile, there is some good news for children born with FASD. Based on research conducted by Ann P. Streissguth and Keiran D. O'Malley—noted in the FASD field for their work—at the University of Washington, the National Institute on Alcohol Abuse and Alcoholism (NIAAA) states that those children with FASD “who receive appropriate supportive services fare better with respect to secondary disabilities and life functioning than those who do not receive such services. Multiple approaches are needed, including social support, special education, behavioral and cognitive therapy, and medications.”<sup>9</sup>

Regarding findings in a subsequent study of 415 FAS and FAE subjects reported in the August 12, 2004, issue of the *Journal of Developmental and Behavioral Pediatrics*, Streissguth offered this hopeful comment: “. . . these children can grow up to have relatively more successful lives.” Streissguth also said that “. . . the odds of escaping these adverse life experiences are improved two-to-four-fold by being diagnosed with FAS or FAE at an early age and by being raised in a good stable environment.”<sup>10</sup>

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<sup>6</sup> Bertrand, J. Floyd, R. L., Weber, M. K., O'Connor, M., Riley, E. P., Johnson, K. A., and Cohen, D. E. (2004). *Fetal alcohol syndrome: guidelines for referral and diagnosis*. Atlanta, GA: CDC, National Center on Birth Defects and Developmental Disabilities. Retrieved January 16, 2008, from [www.cdc.gov/ncbddd/fas/documents/fas\\_guidelines\\_accessible.pdf](http://www.cdc.gov/ncbddd/fas/documents/fas_guidelines_accessible.pdf).

<sup>7</sup> National Center on Birth Defects and Developmental Disabilities. (September 9, 2005). *Fetal alcohol spectrum disorders*. Atlanta, GA: CDC. Retrieved January 16, 2008, from [www.cdc.gov/ncbddd/factsheets/FAS.pdf](http://www.cdc.gov/ncbddd/factsheets/FAS.pdf).

<sup>8</sup> National Center on Birth Defects and Developmental Disabilities. (September 19, 2007). *Fetal alcohol spectrum disorders: intervening with children and/or adolescents with fetal alcohol syndrome or alcohol-related neurodevelopmental disorders*. Atlanta, GA: CDC. Retrieved January 16, 2008, from [www.cdc.gov/ncbddd/fas/intervening.htm](http://www.cdc.gov/ncbddd/fas/intervening.htm).

<sup>9</sup> Warren, K. R., and Foudin, L. L. (2001) Alcohol-related birth defects—The past, present and future. *Alcohol Research and Health*, 25(3), 153-158. Retrieved January 16, 2008, from <http://pubs.niaaa.nih.gov/publications/arh25-3/153-158.pdf>.

<sup>10</sup> University of Washington. (August 13, 2004). New hope for children with fetal alcohol syndrome. *ScienceDaily*. Retrieved January 16, 2008, from [www.sciencedaily.com/releases/2004/08/040812051709.htm](http://www.sciencedaily.com/releases/2004/08/040812051709.htm).

## Facts

- FASD occurs in about 10 per 1,000 live births, or about 40,000 babies per year, according to estimates published in 2001.<sup>11</sup>
- In these 2001 estimates, FAS, the most recognized condition in the spectrum, was estimated to occur in 0.5 to 2 per 1,000 live births.<sup>12</sup>
- FAS outranks Down syndrome and autism in prevalence.<sup>13</sup>
- FASDs last a lifetime—there is no cure. But early identification can improve chances of FASD children receiving services to help increase their well-being.<sup>14</sup>
- Children with an FASD are at very high risk for trouble in school, trouble with the law, alcohol and drug abuse, and mental health disorders.<sup>15</sup>
- In SAMHSA’s 2004 National Survey on Drug Use and Health, one in nine pregnant women reported binge drinking in their first 3 months of pregnancy.<sup>16</sup>
- CDC estimated in 2004 that 1 in 30 pregnant women drink at levels that increase the risk of FASD.<sup>17</sup>

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<sup>11</sup> FASD Center for Excellence. (May 2004). *The language of fetal alcohol spectrum disorders*. Rockville, MD: SAMHSA. Retrieved April 21, 2008, from [www.fasdcenter.samhsa.gov/documents/WYNKLanguageFASD2.pdf](http://www.fasdcenter.samhsa.gov/documents/WYNKLanguageFASD2.pdf).

<sup>12</sup> FASD Center for Excellence. (May 2004). *The language of fetal alcohol spectrum disorders*. Rockville, MD: SAMHSA. Retrieved April 21, 2008, from [www.fasdcenter.samhsa.gov/documents/WYNKLanguageFASD2.pdf](http://www.fasdcenter.samhsa.gov/documents/WYNKLanguageFASD2.pdf).

<sup>13</sup> FASD Center for Excellence. (May 2004). *The language of fetal alcohol spectrum disorders*. Rockville, MD: SAMHSA. Retrieved April 21, 2008, from [www.fasdcenter.samhsa.gov/documents/WYNKLanguageFASD2.pdf](http://www.fasdcenter.samhsa.gov/documents/WYNKLanguageFASD2.pdf).

<sup>14</sup> National Center on Birth Defects and Developmental Disabilities. (September 9, 2005). *Fetal alcohol spectrum disorders*. Atlanta, GA: CDC. Retrieved January 16, 2008, from [www.cdc.gov/ncbddd/factsheets/FAS.pdf](http://www.cdc.gov/ncbddd/factsheets/FAS.pdf).

<sup>15</sup> National Center on Birth Defects and Developmental Disabilities. (September 9, 2005). *Fetal alcohol spectrum disorders*. Atlanta, GA: CDC. Retrieved January 16, 2008, from [www.cdc.gov/ncbddd/factsheets/FAS.pdf](http://www.cdc.gov/ncbddd/factsheets/FAS.pdf).

<sup>16</sup> FASD Center for Excellence. (2007). *Fetal alcohol spectrum disorders by the numbers*. DHHS Publication No. (SMA) 06–4236. Rockville, MD: SAMHSA. Retrieved March 19, 2008, from [www.fasdcenter.samhsa.gov/documents/WYNK\\_Numbers.pdf](http://www.fasdcenter.samhsa.gov/documents/WYNK_Numbers.pdf).

<sup>17</sup> FASD Center for Excellence. (2007). *Fetal alcohol spectrum disorders by the numbers*. DHHS Publication No. (SMA) 06–4236. Rockville, MD: SAMHSA. Retrieved March 19, 2008, from [www.fasdcenter.samhsa.gov/documents/WYNK\\_Numbers.pdf](http://www.fasdcenter.samhsa.gov/documents/WYNK_Numbers.pdf).

- The economic cost to the Nation of FAS alone was estimated in 2004 at up to \$6 billion annually, with the lifetime per-child costs estimated at about \$2 million.<sup>18</sup>
- A 1999 study estimated FAS costs alone at between \$1 million and \$5 million per child. This estimate did not include costs of incarceration or costs to society, such as lost productivity, burden on families, and poor quality of life.<sup>19</sup>

## Federal Resources

### CDC FASD

[www.cdc.gov/ncbddd/fas/default.htm](http://www.cdc.gov/ncbddd/fas/default.htm)

CDC addresses FASD through its FASD program, which focuses on prevention. CDC hosts the National Task Force on FAS/FAE. In addition, diagnostic guidelines are now available online in PDF format, and CDC has a *FASD Prevention Tool Kit for Women's Health Care Providers*, among other FASD-related resources. State data on alcohol consumption rates among women of childbearing age in 2005 are provided in a table and a U.S. map. CDC funds cooperative agreement sites in seven States for the development of comprehensive, State-based FAS prevention programs. A link enables a Spanish-language version of the FASD content.

### Interagency Coordinating Committee on Fetal Alcohol Syndrome

[www.niaaa.nih.gov/AboutNIAAA/Interagency/](http://www.niaaa.nih.gov/AboutNIAAA/Interagency/)

The Interagency Coordinating Committee on Fetal Alcohol Syndrome (ICCFAS) is hosted by NIAAA. The ICCFAS seeks to improve communication, cooperation, and collaboration among disciplines that address health, education, developmental disability, research, justice, and social service issues relevant to FAS and related disorders caused by prenatal alcohol exposure. The committee meets semiannually.

### NIAAA

[www.niaaa.nih.gov/](http://www.niaaa.nih.gov/)

NIAAA supports research in a variety of areas relating to alcohol, coordinates Federal efforts, and translates research into information and products for the public. Areas of research include screening, diagnosis, and treatment of FASD.

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<sup>18</sup> FASD Center for Excellence. (2007). *Fetal alcohol spectrum disorders by the numbers*. DHHS Publication No. (SMA) 06-4236. Rockville, MD: SAMHSA. Retrieved March 19, 2008, from [www.fasdcenter.samhsa.gov/documents/WYNK\\_Numbers.pdf](http://www.fasdcenter.samhsa.gov/documents/WYNK_Numbers.pdf).

<sup>19</sup> FASD Center for Excellence. (May 2004). *The language of fetal alcohol spectrum disorders*. Rockville, MD: SAMHSA. Retrieved April 21, 2008, from [www.fasdcenter.samhsa.gov/documents/WYNKLanguageFASD2.pdf](http://www.fasdcenter.samhsa.gov/documents/WYNKLanguageFASD2.pdf).

## **SAMHSA FASD Center for Excellence**

<http://fasdcenter.samhsa.gov/>

The FASD Center is a Federal initiative devoted to preventing and treating FASD. This Web site provides information and [resources](#) about FASD. The site also provides [materials](#) for raising awareness about FASD.

## **Stopalcoholabuse.gov**

[www.stopalcoholabuse.gov/](http://www.stopalcoholabuse.gov/)

Stopalcoholabuse.gov is a comprehensive portal of Federal resources for information on underage drinking and ideas for combating this issue. People interested in underage drinking prevention—including parents, educators, community-based organizations, and youth—will find a wealth of valuable information here.

## **Private Organizations**

### **FAS Family Resource Institute**

[www.fetalalcoholsyndrome.org/](http://www.fetalalcoholsyndrome.org/)

The FAS Family Resource Institute primarily helps Washington State families better understand FAS or other alcohol-related conditions and publishes a newsletter and other materials.

### **National Organization on Fetal Alcohol Syndrome (NOFAS)**

[www.nofas.org/](http://www.nofas.org/)

NOFAS offers publications and other resources for people living with FASD, expectant mothers, educators, and advocates. The group's Web site acknowledges support from CDC for its information and prevention initiatives.

*Note:* For additional resources relating to FASD and organized by categories, go to <http://fasdcenter.samhsa.gov/links/links.cfm#2>.

## **Strategies/Programs**

*Note:* Strategies and programs for preventing FASD itself have been extensively documented. The searchable database at <http://fasdcenter.samhsa.gov/>—SAMHSA's FASD Center for Excellence—is one useful starting point for those seeking FASD prevention literature and resources. Several of the materials offered in the FASD collection at SAMHSA's Health Information Network—<http://ncadistore.samhsa.gov/catalog/results.aspx?h=issues&topic=230>—include information about preventing FASD from occurring in the first place. The CDC National Center on Birth Defects and Developmental Disabilities (NCBDDD) has an FASD section at [www.cdc.gov/ncbddd/fas/default.htm](http://www.cdc.gov/ncbddd/fas/default.htm) that contains numerous resources. Of particular interest may be the State data on alcohol consumption rates among women of childbearing age in 2005, presented in both table and map formats. Also, there are many sources of recommended “intervention” strategies for families, schools, social services, and others to use in dealing with

children who have long-term disabilities from having been born with FASD. SAMHSA's FASD Center for Excellence is a good source of this, too.

Many States have FASD services with their own Web sites. For example:

Private FASD organizations, such as NOFAS, provide information on working with FASD children as well. Although the focus of these resources is on "interventions," or treatment services for FASD children, several call attention to the increased risk for substance abuse among such children and adolescents.

### **Fetal Alcohol Spectrum Disorders: Developing Intervention Strategies for Children**

[www.cdc.gov/ncbddd/fas/intervening.htm](http://www.cdc.gov/ncbddd/fas/intervening.htm)

CDC-sponsored studies find that children with FAS/ARND are at very high risk for developing secondary conditions such as difficulties in school, trouble with the law, substance abuse problems, and mental health problems. Currently, interventions for children with FAS/ARND are often nonspecific, unsystematic, and/or lack scientific evaluation or validation. Accordingly, CDC is working with grantees "to identify, develop, and evaluate effective strategies for intervening with children with FAS/ARND and their families."

In 2007, those grantees were identified and described on CDC's FASD site as follows:

#### **Marcus Institute—Atlanta, GA**

This intervention focuses on Behavioral Regulation Training (BRT) as a readiness-for-learning strategy and math skills for improving cognition. BRT teaches parents ways to modify the child's environment to reduce excess stimulation, use appropriate social reinforcement, and communicate choices rather than commands. All children in the study population who are diagnosed with FAS or ARND and their families participate in the BRT and are taught self-awareness, decisionmaking, and verbalization of situations and actions. In addition, intervention participants receive individualized math skills training, a common area of significant disability for children with FAS/ARND. The intervention is designed for children aged 3 through 9 years.

#### **University of Washington—Seattle, WA**

The purpose of this project is to explore two intervention models for school-aged children. One consists of an individualized, supportive, behavioral consultation intervention for school-aged children (aged 5 through 11 years) with FAS or ARND. Consultation includes FAS education, emotional/practical support, teaching of child management strategies specific to children with FAS/ARND, advocacy assistance, and school assistance. The second intervention is a school-based social communication intervention provided directly to children with FAS/ARND. This intervention targets critical deficits in social communication and peer relations and is designed to teach children (aged 8 through 12 years) how to use an interactive checklist to guide them through resolution of peer conflicts. An intervention and a control group will be compared using pre- and post-test measures, with post-tests occurring at the conclusion of the intervention and at a 9 month followup.

### **University of Oklahoma Health Services Center—Oklahoma City, OK**

This project uses Parent Child Interaction Therapy (PCIT) to intervene with parents and their children (aged 2 through 7 years) who have been diagnosed with FAS or ARND. The treatment group receives 90-minute group sessions once a week for 14 weeks. Behavioral specialists conduct group sessions with parents to teach them appropriate and effective behaviors and interaction techniques. Parent-child interactions are observed, and individualized guidance is provided. The control group receives standard referrals and services, along with participation in a parent support group. Pre- and post-test comparisons will be made between groups at the conclusion of the intervention and at 6-, 12-, and 18-month followups.

### **University of California—Los Angeles, CA**

This project focuses on parent-assisted social skills training, with particular attention to development of best friend relationships. Children (aged 6 through 8 years) receiving the intervention participate in didactic training sessions, behavior rehearsal, and coaching to reduce maladaptive behaviors and promote pro-social interaction skills. Simultaneously, parents are taught about core deficits of FAS and ARND and given the companion information to their children's intervention. A control group receives standard community care and both groups of participants are re-evaluated at 4 months post-intervention.

### **Children's Research Triangle—Chicago, IL**

This intervention proposes to develop a program of neurocognitive habilitation within a systematic intervention strategy for children with prenatal alcohol exposure. The target population is children (aged 6 through 12 years) diagnosed with FAS or ARND who are currently in the care of the Illinois welfare system. Children and their families are randomized into two groups. Children and families participating in the treatment group receive 12 weeks of neurocognitive habilitation and psychotherapy services along with family education and case management services. Children and families participating in the control group will receive the current standard of care through existing community- and school-based agencies. Pre- and post-measures are analyzed for each group and post-test followup occurs at 12 and 24 months.

In addition, CDC funded development of four curricula for families, professionals, school personnel, and others to help them recognize and understand FAS. These curricula suggest appropriate services for children with FAS and their families. More information about the curricula and links to the nonprofit organizations that created them are available at [www.cdc.gov/ncbddd/fas/awareness.htm](http://www.cdc.gov/ncbddd/fas/awareness.htm).

### **Successfully Raising Resilient Foster Children Who Have Fetal Alcohol Syndrome: What Works?**

[www.envisionjournal.com/application/main.aspx?MainFormOption=2](http://www.envisionjournal.com/application/main.aspx?MainFormOption=2)

This article from the April 2004 issue of *Envision* describes the author's examination of the factors that contribute to successful foster home placement for children with FASD through a study conducted with long-term foster parents fostering through a First Nation child welfare

agency in western Manitoba. The article explores the experiences of foster parents raising children with FASD, paying particular attention to some of the specific problems facing parents of adolescents.