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# Supporting Parents of Children with Fetal Alcohol Spectrum Disorders, and Young Children with Significant Prenatal Alcohol Exposure

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## Introduction

Fetal alcohol spectrum disorders (FASD) are lifelong, wide-ranging developmental disabilities caused by prenatal alcohol exposure (PAE). FASD is a global health problem[1] with high personal and societal costs.[2-3] Families across all ethnicities and socioeconomic levels are impacted. Some studies have estimated rates of the full range of conditions within FASD as high as 9 or 10 per 1,000 live births,[4-5] with greater prevalence in certain high-risk groups.[6-8] New prevalence data from systematic school screening further heightens concern.[9] Needs assessment data make clear

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that parents raising children with FASD require a range of support and family-focused services over the lifespan.[10]

**Subject**

Families bear the main responsibility for care of children with FASD. Young children at risk for FASD due to significant PAE often show developmental or behavioural difficulties.[11-12] Individuals with FASD typically show lasting learning problems, maladaptive behaviour, low adaptive function. They can show various “secondary disabilities,” most commonly mental health problems, but sometimes also such lifestyle problems as disrupted school experiences, trouble with the law or employment difficulties.[3,13-14] Both groups often experience associated social problems and caregiving instability[3,12,15] that may increase risk of or help to explain negative outcomes.[16-18] Parents must often provide more intensive assistance to children with FASD than expected for age, in childhood[19] and into adulthood.[3] Whether in birth, adoptive, foster or kinship homes, caregivers raising children with FASD usually experience high caregiving stress and have many unmet family needs.[20-23] But a good quality caregiving environment, with a supportive parental presence and a stable, structured, consistent home,[24] is important to reduce risks of secondary disabilities in FASD,[3] and improve outcomes for children born alcohol-exposed.[25] Early research and practical experience provide models for parent support and family-focused intervention.

**Problems**

Improved education, identification and service eligibility requirements needed. Community education about PAE and FASD remains incomplete, with misinformation still prevalent. Identification of affected individuals is still limited. Parents must often engage in advocacy just to receive help from multiple service systems.[10,12] Qualification for services is often based on criteria other than FASD, so services received may not be appropriate. There can also be social stigma about FASD, and societal resistance toward allocating resources to treat a preventable condition. All this means inadequate parent support.

A wide range of services needed. Support to birth parents must sometimes involve FASD prevention. FASD can be a “transgenerational” problem, as some affected individuals may have a child with FASD and need intensive parenting support.[26-27] FASD and PAE are often associated with psychosocial disruption, and these issues complicate or pose barriers to support and services. Services adapted to or specialized for FASD, or children at high risk because of PAE, are often

needed but rarely available. Because FASD occurs so widely, services must be adjusted to work in different communities and cultures.

Intervention research needed. Although guidelines exist for a standard of care, evidence-based best practices for parent support and family-focused services for FASD have not been established. This is because there has been little descriptive or systematic intervention research, and only limited program evaluation of community intervention efforts so far.

**Research Context**

Systematic research attention to the characteristics, needs and strengths of families and individuals with FASD,[23] and to the development and testing of FASD interventions, has recently emerged. Guiding this research are the families' own first-person accounts, results of large-scale community needs assessments,[10] information derived from the experience within parent support networks,[28] and accrued clinical wisdom.[1, 29-34] But little is known about families raising individuals with FASD, and about what are risk and protective factors for this population. Importantly, there is marked concern about the small amount of existing intervention research, and in particular studies with robust research design.[35-38]

Limited descriptive research about this population exists at this time. There is pioneering developmental research tracing early life paths for young children with significant PAE, and natural history research on risk and protective factors for individuals with FASD ranging in age from preschool to adulthood.[3,39-40] To move forward, researchers interested in parent and family support for FASD are turning to related literatures for guidance.[23,41] Data from study of developmental disabilities, and traumatic brain injury, for example, reveal that formal support to parents, case management, parent training in behavioural principles, strong "informal" parent-to-parent contact, and group interventions especially using cognitive-behavioural therapy all reduce caregiving stress,[42] and can lead to other aspects of positive individual and family function[43] (especially with multi-component interventions).[44] When disabilities and challenging behaviour co-occur, positive behaviour support interventions are useful,[45] and specific caregiving attitudes are central to positive outcome.[46-47] Developmental research supports use of early parent-child relationship-building intervention methods.[41,48] The coping literature indicates that caregiver sense of "perceived support" (vs. "received support") predicts positive outcome, and highlights the importance of a wide range of caregiver coping skills.[49-50]

**Key Research Questions**

*Descriptive data*

1. What are the “lived experiences,” needs and strengths of parents raising a child with FASD, or young child at risk because of significant PAE?
2. What are pivotal risk and protective factors in caregiving attitudes, motives, coping styles and parenting practices?
3. How do patterns of lived experiences, and risk and protective factors, in FASD compare to those in other disabilities? And how do they differ by: Family type? Developmental stage? Severity of child’s impairment? Cultural groups?
4. What are the gaps in existing parent support and family-focused services?

*Effects of training and intervention*

5. What types of provider training improve services within different service systems?

6. What are the effects of informal/natural parent support mechanisms (on-line, support groups, parent-to-parent support, etc.)? How must parent support be adjusted across the lifespan?

7. What types of respite are most beneficial to family adaptation?

8. What specialized parent education and parenting interventions are efficacious in improving individual and family outcome in FASD, at different ages and for different family types?

9. How do existing evidence-based parenting interventions (developed for other populations with similar symptoms) work for FASD, and how should they be adapted?

*Translational Research*

10. How can efficacious interventions be rapidly disseminated to community settings? What delivery systems increase efficiency, availability and cost-effectiveness of useful interventions (e.g., on-line, group formats, telemedicine)?

**Recent Research Results**

Current research describes “lived experiences” in a few small samples of caregivers raising children with FASD in several countries. Experiences differ between family types. Research reveals specific family needs and difficulties to be remediated, and effective parenting practices and positive child characteristics to be promoted in intervention.[21-23,51] Reviewers are mining other literatures to find useful treatment methods,[23,41] and critically examining the small database of existing FASD intervention research.[35-38,48] Reviews show little research focus so far on how to help families raising an individual with FASD,[38] though limited data do show that parenting interventions can lead to measurable improvement in caregiver and child outcomes. Enhancing quality of the parent–child relationship, decreasing parenting stress, fostering effective parenting skills, and increasing parents’ sense of self-efficacy are all deemed critical components of any parenting intervention.[48]

Services to support families are often recommended in FASD diagnostic clinics, with treatment needs showing developmental trends.[52] Researchers are slowly identifying a range of efficacious parent support and family-focused interventions. There has been some evaluation of community programs. Qualitative evaluation of province-wide “key worker and parent support” programs in Canada, for example, suggests gains in caregiver, child and community outcomes.[53] In the U.S., systematic intervention research funded by the Centers for Disease Control and Prevention (CDC) has focused on caregivers of preschool and school-aged children with PAE or FASD. Among other findings, data reveal that specialized parent education groups do increase caregiver knowledge, and specialized behavioural consultation for caregivers of children with FASD and problem behaviour do improve caregiving and child outcomes.[54-57] These interventions are being translated into community settings. This research also shows how existing interventions should generally be adapted for FASD, with specific adaptations noted by some researchers[58] and experts.[34] CDC is now funding pilot study of a multi-component, intensive family-focused FASD intervention for the adolescent and young adulthood years.[59] In the U.S., research funded by the National Institutes of Health is examining the feasibility of multi-component early intervention services for families of young children at high risk because of PAE and electronic resources to more efficiently assist caregivers.[a]

**Research Gaps**

There are many research gaps. Population-specific descriptive data remain remarkably limited. Multiple samples must be assessed because of diversity in this clinical population, and variation in

how services are provided across locations. Secondary data analysis should examine how typical interventions work for those with PAE or FASD. Key treatment ingredients must be identified. Evaluation of the impact of provider training, informal/natural parent support mechanisms, respite care, parent education, and specialized parenting interventions on caregiving, family quality of life and individual outcomes is needed using strong research design. Specialized parenting intervention models already shown to be efficacious should be replicated. Special focus is needed on developing treatments for underserved groups (families raising very young children with PAE or adolescents/young adults with FASD), and on comprehensive interventions that address FASD and co-occurring psychosocial disruption.[49] Translational research is important, to find how efficacious interventions can be disseminated and made most accessible and cost-effective.

**Conclusions**

It is surprising that a disability as common and burdensome to families as FASD still so often goes unrecognized or not appropriately served. Social and economic factors play a role. These include the pervasiveness of alcohol use in almost all societies, stigma and misconceptions about those affected, complexity of needed services, and resource limitations. A good quality, stable caregiving environment is important to improve outcomes for FASD and young children at high risk due to PAE, and to reduce the risks for secondary disabilities. This, in turn, means lower societal costs. A wide range of parent support and family-focused services are needed but not yet available. Systematic FASD intervention research has begun, with promising results showing improved outcomes for parents and affected individuals, and successful efforts to disseminate interventions to community settings. “Practice-based evidence” on interventions has been compiled, and program evaluation is starting. But funding for increased intervention and translational research is essential.

**Implications for Parents, Services and Policy**

Parent support and family-focused services are an essential response to the global public health problems of FASD and PAE. Across cultures, parents and families shoulder the care of those with the lifelong disability of FASD. They must often provide intensive caregiving as their child grows into young adulthood and beyond, when societal supports are especially scarce. Data clearly show that a good home environment provides a set of protective factors related to higher odds of more positive life outcomes for individuals affected by FASD. The spontaneous, rapid growth of parent support networks since the 1990s anecdotally confirms that parent support is helpful to families.[28]

But building a good home environment, and acting as an effective advocate for service access, generally requires more than self-help through networking with other parents. Customized, family-focused services are often necessary. Research has started to create and test appropriate intervention models for such services. Parents can play a key and compelling role in educating policy makers about the pressing, growing need for accessible, appropriate, effective family-focused services. Parents can be instrumental in bringing about the action steps listed below.

Below are proposed as action steps to build parent support and family-focused services and policy in the field of FASD:

1. Carry out multifaceted, culturally-sensitive educational campaigns and provider training to raise awareness, reduce stigma, increase identification and improve service provision.
2. Promote and evaluate caregiver self-help through natural/informal parent support mechanisms as a low-cost response in a time of resource constraints.
3. Conduct a comprehensive review of existing community-based intervention efforts in order to identify gaps and compile program evaluation data.
4. Evaluate all ongoing and future community-based programs that provide parent support and family-focused services.
5. Disseminate specialized FASD interventions already found to be efficacious, including parent education and behavioral consultation, adapting these to suit different communities and cultures.
6. Develop and test additional parent support and family-focused intervention approaches to fill service gaps. (These should be based on population-specific descriptive data and draw from related literatures, including testing whether existing evidence-based parenting interventions are useful for families raising individuals with FASD or PAE.)
7. Establish a standard of care and best practices for parent support and family-focused services. Once established, establish policy to promote adherence to the standard of care.

**References**


1. SAMHSA Fetal Alcohol Spectrum Disorders (FASD) Center for Excellence Web site. Available at: http://www.fasdcenter.samhsa.gov. Accessed February 9, 2011.
2. Lupton C, Burd L, Harwood R. 2004. Cost of fetal alcohol spectrum disorders. *Am J Med Genet*. 2004;127C:42-50.

3. Streissguth AP, Bookstein FL, Barr HM, Sampson PD, O'Malley K, Young JK. Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *J Dev Behav Pediatr*. 2004;25(4):228-238.
4. May PA, Gossage JP. 2001. Estimating the prevalence of fetal alcohol syndrome: a summary. *Alcohol Res Health*. 2001;25:159–167.
5. Sampson PD, Streissguth AP, Bookstein FL, Little RE, Clarren SK, Dehaene P, Hanson JW, Graham JM Jr.. Incidence of fetal alcohol syndrome and prevalence of alcohol-related neurodevelopmental disorder. *Teratol*. 1997;56:317-326.
6. Fast DK, Conry J, Loock CA. Identifying fetal alcohol syndrome among youth in the criminal justice system. *J Dev Behav Pediatr*. 1999;20:370-372.
7. Landgren M, Svensson L, Stromland K, Andersson GM. Prenatal alcohol exposure and neurodevelopmental disorders in children adopted from Eastern Europe. *Pediatrics*. 2010;125(5):pp. e1178-1185.
8. Astley S, Stachowiak J, Clarren S, Clausen C. Application of the fetal alcohol syndrome facial photographic screening tool in a foster care population. *J Pediatr*. 2002;141(5):712-717.
9. May PA, Gossage JP, Kalberg WO, Robinson LK, Buckley D, Manning M, Hoyme HE.. Prevalence and epidemiologic characteristics of FASD from various research methods with an emphasis on recent in-school studies. *Dev Disabil Res Rev.* 2009;15:176-192.
10. Ryan D, Bonnett D, Gass C. Sobering thoughts: town Hall meetings on fetal alcohol spectrum disorders. *Am J Public Health*. 2006;96(12):2098-2101.
11. O'Connor MJ. Prenatal alcohol exposure and infant negative affect as precursors of depressive features in children. *Infant Ment Health J*. 2001;22(3):291-299.
12. Olson H, Jirikowic T, Kartin D, Astley S. Responding to the challenge of early intervention for fetal alcohol spectrum disorders. *Infants Young Children*. 2007; 20(2):172-189.
13. O'Connor MJ, Paley B. Psychiatric conditions associated with prenatal alcohol exposure. *Dev Disabil Res Rev*. 2009;15(3):225-234.
14. Kodituwakku P. Neurocognitive profile in children with fetal alcohol spectrum disorders. *Dev Disabil Res Rev*. 2009;15(3):218-224.
15. Miller KA. Exploring placement instability among young children in the multidimensional treatment foster care preschool study. *Dissertation Abstracts International: Section B: The Sciences and Engineering*, 2008;68(10-B):6974.
16. Hannigan JH, Berman RF. Amelioration of fetal alcohol-related neurodevelopmental disorders in rats: exploring pharmacological and environmental treatments. *Neurotoxicol Teratol*. 2000;22:103-111.
17. Coggins T, Timler G, Olswang L. A state of double jeopardy: impact of prenatal alcohol exposure and adverse environments on the social communicative abilities of school-age children with fetal alcohol spectrum disorder. *Lang Speech Hear Serv Sch.* 2007;38(2):117-127.
18. Henry J, Sloane M, Black-Pond C. Neurobiology and neurodevelopmental impact of childhood traumatic stress and prenatal alcohol exposure. *Lang Speech Hear Serv Sch*. 2007;38(2):99-108.
19. Jirikowic T, Kartin D, Olson H. Children with fetal alcohol spectrum disorders: a descriptive profile of adaptive function. *Can J Occup Ther.* 2008;75(4):238-248.
20. Paley B, O'Connor M, Frankel F, Marquardt R. Predictors of stress in parents of children with fetal alcohol spectrum disorders. *J Dev Behav Pediatr*. 2006;27(5):396-404.
21. Brown JD, Sigvaldason N, Bednar LM. Motives for fostering children with alcohol-related disabilities. *J Child Fam Stud*. 2007;16(2):197-208.

22. Salmon J. Fetal alcohol spectrum disorder: New Zealand birth mothers' experiences. *Can J Clin Pharmacol*. 2008;15(2):e191-213.

23. Olson H, Oti R, Gelo J, Beck S. "Family matters:" fetal alcohol spectrum disorders and the family. *Dev Disabil Res Rev.* 2009;15(3):235-249.

24. Olson, H, O'Connor, M, Fitzgerald, H. Lessons learned from study of the developmental impact of parental alcohol use. *Infant Ment Health J.* 2001;22, 271-290.

25. Niccols A, Sword W. ''New choices'' for substance using mothers and their young children: preliminary evaluation. *J Substance Use*. 2005;10:239–251.

26. O'Malley K, Streissguth, A. Clinical intervention and support for children aged zero to five years with fetal alcohol spectrum disorders and their parents/caregivers. Rev ed. In Tremblay RE, Barr RG, Peters RDeV, eds. *Encyclopedia on Early Childhood Development* [online]. Montreal, Quebec: Centre of Excellence for Early Childhood Development. 2005;1-9. Available at: http://www.child-encyclopedia.com/documents/OMalley-StreissguthANGxp_rev.pdf. Accessed February 9, 2011.

27. Grant T, Huggins J, Connor P, Pedersen JY, Whitney N, Streissguth A. A pilot community intervention for women with fetal alcohol spectrum disorders. *Commun Ment Health J.* 2004;40:499-511.

28. Wilton G, Plane MB. The family empowerment network: a service model to address the needs of children and families affected by fetal alcohol spectrum disorders. *Pediatr Nurs.* 2006;32(4):299-306.

29. Kleinfeld J, Wescott S. *Fantastic Antone succeeds! : experiences in educating children with fetal alcohol syndrome*. Fairbanks, AK: University of Alaska Press; 1993.

30. Streissguth AP. *Fetal alcohol syndrome : a guide for families and communities*. Baltimore, MD: Brookes Publishing; 1997.

31. Kalberg W, Buckley D. FASD: what types of intervention and rehabilitation are useful? *Neurosci Biobehav Rev.* 2007;31(2):278-285.

32. Bertrand J, Floyd RL, Weber MK, O'Connor M, Riley EP, Johnson KA, Cohen DE, NTFFAS/E. *Fetal alcohol syndrome: guidelines for referral and diagnosis*. Atlanta, GA: Centers for Disease Control and Prevention;2004

33. Chudley AE, Conry J, Cook JL, Loock F, Rosales T, Le Blanc N. Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *CMAJ.* 2005;172(5 suppl):s1-s21.

34. Adubato S, Cohen D, eds. *Prenatal alcohol use and fetal alcohol spectrum disorders: diagnosis, assessment and new directions in research and multimodal treatment*. United Kingdom: Bentham Science eBooks. In press.

35. Burd L, Christensen T. Treatment of fetal alcohol spectrum disorders: are we ready yet? *J Clin Psychopharmacol.* 2009;29:1–4.

36. Peadon E, Rhys-Jones B, Bower C, Elliott E. Systematic review of interventions for children with fetal alcohol spectrum disorders. *BMC Pediatr. 2*009;9:35.

37. Premji S, Benzies K, Serrett K, Hayden K. Research-based interventions for children and youth with a fetal alcohol spectrum disorder: revealing the gap. *Child Care Health Dev.* 2007;33(4):389-397.

38. Chandrasena AN, Mukherjee RAS, Turk J. Fetal alcohol spectrum disorders: an overview of interventions for affected individuals. *Child Adol Ment Health*. 2009;14(4):162-167.

39. O'Connor MJ, Paley B. The relationship of prenatal alcohol exposure and the postnatal environment to child depressive symptoms. *J Pediatr Psychol*. 2006;31(1):50-64.

40. O'Connor MJ, Sigman M, Kasari C. Interactional model for the association among maternal alcohol use, mother-infant interaction, and infant cognitive development. *Infant Behav Dev*. 1993;16(2):177-192.

41. Olson HC, Montague RA. An innovative look at early intervention for children affected by prenatal alcohol exposure. In: Adubato S, Cohen D, eds. *Prenatal alcohol use and fetal alcohol spectrum disorders: diagnosis, assessment and new directions in research and multimodal treatment*. United Kingdom: Bentham Science eBooks. In press.

42. Hastings R, Beck A. Practitioner review: stress intervention for parents of children with intellectual disabilities. *J Child Psychol Psychiatry*. 2004;45:1338-1349.

43. Bailey DB. Introduction: family adaptation to intellectual and developmental disabilities. *Ment Retard Dev Disabil Res Rev.* 2007;132:291-292.

44. Singer GHS, Ethridge BL, Aldana SI. Primary and secondary effects of parenting and stress management interventions for parents of children with developmental disabilities. *Ment Rretard Dev Disabil Res Rev.* 2007;13:257-269.

45. Lucyshyn JM, Dunlap G, Albin RW. *Families and positive behavior support: addressing problem behaviors in family contexts.* Baltimore, MD: Brookes Publishing;2002.

46. Hasall R, Rose J, McDonald J. Parenting stress in mothers of children with an intellectual disability: the effects of parental cognitions in relations to child characteristics and family support. *J Intell Disabil Res*. 2005;49:405-418.

47. Blacher J, Baker BL. Positive impact of intellectual disability on families. *Am J Ment Retard*. 2007;112:330-348.

48. Paley B, O'Connor M. Intervention for individuals with fetal alcohol spectrum disorders: treatment approaches and case management. *Dev Disabil Res Rev*. 2009;15(3):258-267.

49. Pottie CG, Ingram KM. Daily stress, coping and well-being in parents of children with autism: a multilevel modeling approach. *J Fam Psychol*. 2008;22(6):855-864.

50. Pottie CG, Cohen J, Ingram KM. Parenting a child with autism: contextual factors associated with enhanced daily parental mood. *J Pediatr Psychol*. 2009;34(4):419-429.

51. Morrissette PJ. Fetal alcohol syndrome: parental experiences and the role of the family counselor. *Qualitive Report.* 2001;6(2).

52. Jirikowic T, Gelo J, Astley S. Children and youth with fetal alcohol spectrum disorders: A summary of services, supports, and resources following clinical diagnosis. *Intellec Dev Disabil.* 2010:48(5):330-334.

53. Hume S, Rutman D, Hubberstey C, Lentz T, Sandy N, Van Bibber M. *Key worker and parent support program: time 1 summative evaluation report*. British Columbia, Canada: Ministry of Children and Family Development; Apr 2008.

54. Bertrand J, Consortium IfCwFASDR. Interventions for children with fetal alcohol spectrum disorders (FASDs): overview of findings for five innovative research projects. *Res Dev Disabil.* 2009;30(5):986-1006.

55. O'Connor MJ, Frankel F, Paley B, Schonfeld AM, Carpenter E, Laugeson EA, Marquardt R. A controlled social skills training for children with fetal alcohol spectrum disorders. *J Consult Clin Psychol.* 2006;74(4):639-648.

56. Coles CD, Kable JA, Taddeo E. Math performance and behavior problems in children affected by prenatal alcohol exposure: Intervention and follow-up. J Dev Behav Pediatr. 2009;30(1):7-15.

57. Olson HC, Brooks A, Quamma J, Lehman K, Ranna M, Davis C, Kerns K, Astley S. Efficacy of a new model of behavioral consultation for families raising school-aged children with FASDs and behavior problems. In preparation.

58. Laugeson EA, Paley B, Schonfeld A, et al. 2007. Adaptation of the children's friendship training program for children with fetal alcohol spectrum disorders. *Child Fam Behav Ther*. 2007;29:57-69.

59. Bertrand J, Dang E, O'Connor MJ, Tenkku L, Olson HC, Grant T. Centers for Disease Control and Prevention funded interventions for youth and young adults with fetal alcohol spectrum disorders. Poster presented at: The Fourth Biennial National Conference on Adolescents and Adults with Fetal Alcohol Spectrum Disorder. April 14-17, 2010.Vancouver: BC.

**Note:**

[a] See also  The National Institutes of Health, Research Portfolio Online Reporting Tools, Reports, Research and Data Analyses of NIH Research Activities. Project Listing By Category: Fetal alcohol syndrome:  Paley B.  Fostering self-regulation in infants and toddlers with fetal alcohol spectrum disorders.  And  Bruss C.  Improving the lives of children with fetal alcohol spectrum disorders: an e-learning resource for caregivers.  Available at: http://report.nih.gov/rcdc/categories/ProjectSearch.aspx?FY=2009&ARRA=N&DCat=Fetal Alcohol Syndrome. Accessed February 8, 2011.