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Interventions in Fetal Alcohol Spectrum Disorders: An International Perspective

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Abstract

Fetal alcohol spectrum disorders (FASD) are present across countries and cultures, with prevalence rates threatening to rise in the coming years. In order to support children and families with FASD around the world, researchers must work to disseminate and implement evidence-based interventions. However, each cultural context presents unique elements and barriers to the implementation process. This review considers the challenges of addressing FASD in an international context. It summarizes existing FASD interventions that have empirical support in the domains of parenting and education, attention and self-regulation, adaptive functioning, and nutrition and medication. It then outlines cultural barriers pertaining to FASD that may impede the implementation process and makes suggestions for using purveyors as cultural liaisons between researchers and local stakeholders. The review concludes with recommendations for moving forward with international dissemination and implementation of FASD interventions.

Keywords: fetal alcohol syndrome; FASD; interventions; cultural barriers; implementation

Interventions in Fetal Alcohol Spectrum Disorders: An International Perspective

Fetal alcohol spectrum disorders (FASDs) are prevalent worldwide. In the United States, active-case ascertainment studies estimate that 2-5 percent of first-grade students have an FASD (May et al., 2014). Prevalence rates outside of the United States vary, with some of the highest rates reported in certain regions of South Africa, ranging as high as 13 to 20 percent (May et al., 2013). Researchers have warned that the worldwide prevalence of FASD may increase in the coming years (Popova et al., 2014). These suspicions are supported by increasing rates of binge drinking and drinking during pregnancy (Lim et al., 2012; Thomas, 2012; WHO, 2011) and growing rates of unplanned pregnancies (Alvanzo & Svikis, 2008; Balachova et al., 2012; Hartley et al., 2011). Unfortunately, prevalence rates of FASD are lacking in many countries and regions of the world, which limits our knowledge of the magnitude and variation of this major public health problem worldwide. Even among countries where prevalence rates are available, FASD is still under-recognized among the general public, providers, and policy makers alike. Given the considerable financial and caregiving burden FASD places on families and societies, recognition and treatment should be a worldwide priority.

In 2010, the World Health Organization (WHO) proposed a global strategy to address alcohol use worldwide, including preventing and identifying alcohol use among pregnant women and women of childbearing age (WHO, 2010). In this assembly, the WHO also highlighted the importance of improving the capacity for nations worldwide to treat and care for families and individuals affected by FASD. Efforts to implement this strategy, however, are still in the early stages. Despite a growing literature on FASD, many countries struggle to accumulate research data in this area. Various cultural barriers also impede progress, such as recognition of FASD and implementation of interventions at policy and program levels. Further, research on

empirically supported interventions for individuals and families with FASD is still in its early stages. Recent reviews have been published to consolidate this evidence base (Kodituwakku & Kodituwakku, 2011; Paley & O'Connor, 2009; Petrenko, 2015; Reid et al., 2015), but little work has been done to determine the appropriateness and efficacy of these interventions beyond the national context in which they were developed.

Implementation science is a field of research that works to integrate studies on interventions into policy and clinical practice. Although there are various guidelines available for approaches to implementation (e.g. Kelly & Perkins, 2012; National Institutes of Health Fogarty International Center, n.d.; Applied Mental Health Research Group (AMHR), 2000), there is no gold standard for transporting evidence-based interventions to different cultural contexts. Evidence-based interventions in domains of mental health outside FASD have been successfully implemented in international contexts using different strategies. For instance, Child-Parent Psychotherapy was implemented in Israel through a bottom-up dissemination process (David & Schiff, 2015). Trauma-Focused Cognitive Behavioral Therapy was successfully implemented in Zambia via the Design, Implementation, Monitoring, and Evaluation (DIME) model (Murray et al., 2013). For FASD in particular, a prevention protocol derived from two empirically supported interventions was successfully implemented in Russia using focus groups, surveys, and a randomized control trial (Balachova et al., 2007, 2013, 2014). Despite these differences in approach, a universal part of international implementation involves understanding the behaviors and attitudes of local providers and stakeholders. This is especially relevant for international work because cultural differences and unique systems barriers may need to be sensitively addressed (e.g. Petrenko, Tahir, Mahoney, & Chin, 2014; Elliott, 2013).

This review considers the challenges of addressing FASD in an international context. It summarizes existing FASD interventions that have empirical support and outlines cultural barriers pertaining to FASD that may impede the implementation process. The review concludes with recommendations for moving forward with international dissemination and implementation of FASD interventions.

Evidence-Based FASD Interventions

Research on interventions for individuals with FASD has been increasing in recent years. While most current interventions focus on preschool and school-aged children, new programs continue to be developed, building the evidence base for effective programs across the lifespan. Programs target a range of domains, including parent education and training, attention and self-regulation, adaptive functioning, nutrition, and medication. Researchers, policy makers, and providers will want to consider factors such as intervention content, target age of child/adult, setting of delivery, type of provider, format of sessions, frequency and duration of sessions, and empirically supported outcomes when selecting interventions for implementation, adaptation, or further evaluation. The following section consolidates available evidence for current interventions by domain of focus (see Table 1 for a summary).

Table 1

FASD Interventions

Program Name	Content	Target age of child	Setting	Counselor	Format	Frequency/ Duration	Outcomes	References
Parent Education and Training						O		
Parent-Child Assistance Program (P-CAP)	Provides women with alcohol and substance use problems support connecting to community resources, coordinating services, and ensuring a safe environment for mother and child.	0-3 years	Home	Paraprofessi onal with similar personal experiences	Mentoring, individualized programming, advocacy	3 years, starting weekly and decreasing to twice monthly	No effect of intervention on development scores at age 3	Kartin et al., 2002
Break the Cycle (BTC)	Focuses on the parent- child relationship with substance-abusing mothers and their young children by offering a comprehensive and coordinated range of services.	Infancy to toddlerhood	Commu nity	Dependent on services accessed	Single access model of integrated services, including home visitation and outreach	Needs basis	Decreased maternal substance use, improved maternal mental health, increased relationship capacity, improved child outcomes	Koren, 2013
Parent training workshops and psychoeducation	Educates families about FASD, information on effecive behavior management strategies, and advocacy tools.	3-10 years	Home or clinic	Clinical psychologist	Information packets, caregiver workshops, web- based programs	Variable	Satisfaction with all intervention formats, increased parent knowledge, improved behavioral functioning	Coles, Kable, & Taddeo, 2009; Kable, Coles, & Taddeo, 2007; Kable, Coles, Strickland, et al., 2012; Bertrand, 2009: study 4
Coaching Families (CF) Program	Educates families about FASD, helps them access resources, and engages them in successful advocacy.	1-23 years	Home	Mentor with 2 years post secondary education and 2 years field experience	Family goal- based mentoring	Needs basis	Decreased needs, increased goal attainment, decreased caregiver stress	Leenaars, Denys, Henneveld, et al., 2012

	Parent-Child Interaction Therapy (PCIT)	Focuses on improving the parent-child relationship, increasing appropriate social skills, reducing problem behavior, and creating a positive discipline program.	3-7 years	Clinic, home with modific ations	Master's level mental health counselor	Group-based adaptation; Parent-child dyad with in vivo coaching	14 weeks, once a week, 90 minutes	Improved child behavior problems, decreased parent stress; outcomes did not differ from moderate intensity psychoeducation and support group	Bertrand, 2009: study 4
	Families Moving Forward (FMF)	Modifies specific parenting attitudes and responses toward child problem behavior to reduce child problem behavior and improve family functioning.	5-11 years	Home	Trained mental health provider	Individualized caregiver training	9-11 months, every two weeks, 90 minutes	Improved parenting self-efficacy and self- care, family needs met, reduced child problem behavior	Bertrand, 2009: study 5
	Parent-Child Assistance Program (P-CAP) for Mothers with FASD	Provides women with alcohol and substance use problems support connecting to community resources, coordinating services, and ensuring a safe environment for mother and child.	Adult	Home	Paraprofessi onal advocate case manager	Case management and support	3 years	Reduced drug and alcohol use, increased utilization of medical and mental health case services, greater use of contraception, acquisition of stable housing	Grant, Huggins, Connor, et al., 2004
	Step-by-Step Program	Uses family mentors to help parents meet family needs and achieve individualized goals regarding housing, addiction treatment, financial supports, and parenting supports.	Adult	Home	Family mentor	1:1 mentoring	3 years	Reduced needs and achieved goals	Denys, Rasmussen, & Henneveld, 2009
Se	ttention and elf-Regulation Computerized Progressive Attention Training (CPAT)	Uses computerized training on four tasks in combination with coaching in metacognitive strategies and support.	8-15 years	School	Assistant with secondary education	1:1 coaching	16 hours, 4 times a week, 30 minutes	Improved sustained and selective attention, spatial working memory, and reading and math fluency	Kerns et al., 2010

Pay Attention Program	Focuses on improving visual and auditory attention through graded activities	6-12 years	School	Experimente r	Individual	12 daily 30-minutes sessions	Improvements in visual and auditory sustained attention, selective attention, and alternating attention; nonverbal reasoning; no group differences on teacher reports of attention	Vernescu, 2009
Rehearsal training	Teaches children rehearsal strategies to improve working memory.	4-11 years	Clinic	Experimente r	Individual	2 sessions	Increased memory for numbers	Loomes et al., 2008;
Cognitive Control Therapy (CCT)	Reorganizes cognitive controls and maladaptive strategies that undermine classroom performance. Teaches children how to think and engage in self-observation and self-regulation.	8-9 years	School	Trained and experienced therapist	Individual	10 months, once a week, 1 hour	Improved behavior and adaptive functioning in the classroom, no effects in meta-cognitive skills or neuropsychological functioning	Riley, Mattson, Li, et al., 2003
GoFAR	Teaches children affective and metacognitive control strategies using a computer game and behavioral training.	5-10 years	Clinic	Trained therapist	Individual	10 sessions, 1 hour	Decreased disruptive behavior (parent report)	Coles et al., 2015
Alert Program for Self-Regulation	Targets self-regulation skills through sensory integration and cognitive processing activities organized in 3 successive stages.	8-12 years	Clinic	Doctoral level psychologist	Individual	12 weeks	Improved inhibition naming, affect recognition, and parent-reported behavioral regulation, no change social skills or behavioral problems, brain structure changes: increases in grey matter	Nash et al., 2015; Wells, Chasnoff, Schmidt, et al., 2012; Williams & Shellenberger, 1996; Soh et al., 2015

Parents and Children Together (PACT)	Incorporates components of the Alert Program for Self-Regulation and treatment strategies from the traumatic brain injury literature.	6-12 years	Clinic	Licensed or doctoral level mental health specialist	Child and parent groups	12 weeks	Improved parent- reported executive functioning and child emotional problem solving	Study #3 in Bertrand, 2009; Wells et al., 2012
Adaptive								
Functioning Fire and street safety virtual training	Trains children in 4 concrete safety skills for fire safety or street safety using a video game. An animated dog teaches child skills in small incremental steps and restricts incorrect or dangerous movements.	4-10 years	Clinic, home, school	Adult supervision to ensure mastery of content	Individual	Game played to mastery (<30 min)	Improved knowledge, ability to generalize knowledge to behavioral setting	Padgett et al., 2006; Coles et al., 2007
Good Buddies	Emphasizes friendship skills. Tailored to the neurodevelopmental needs of children with FASD. Caregiver group focuses on how to support children's friendships and social skills.	6-12 years	Clinic	Doctoral level psychologist	Child and parent groups	12 weeks	Improved child use and knowledge of social skills, decreased hostile attribution in peer entry situations, improved behavior problems (parent report), better outcomes if taking neuroleptic medications, improved child self-concept, equally effective for children with FASD vs. not	Study #1 in Bertrand, 2009; Frankel et al., 2006; Keil et al., 2010; O'Connor et al., 2006; O'Connor et al., 2012
Kid's Club	Facilitates the development of social skills while addressing sensory needs, providing structure and consistency, having a low child-adult ratio, and involving	7-12 years	Commu nity	Occupationa 1 therapist	Child and parent groups	7 weeks, once a week, 90 minutes	Gains in parent-rated social skills	Sparks-Keeney et al., 2011

caregivers

Literacy and Language Training (LLT)	Focuses on language therapy, phonological awareness, and literacy training.	9-10 years	School	Speech and language therapist	Small group	9 months, twice a week, 30 minutes	Gains in specific categories of language and literacy, no group differences in general scholastic achievement battery	Adnams et al., 2007
Math Interactive Learning Experience (MILE)	Includes individualized tutoring for the child, parent instruction and "athome" activities to support generalization of skills, parent workshops, and case management and consultation as needed to support the child's readiness to learn.	3-10 years	Clinic, school, commu nity sites	Trained instructor with secondary education	Child tutoring, parent training, consultation	6 weeks	Gains in math functioning post- intervention and 6 months later, no differences between University and Community outcomes	Kable et al., 2015; Coles, Kable, & Taddeo, 2009; Kable, Coles, & Taddeo, 2007; Kable, Taddeo, Strickland, et al., 2015
Project Step-Up	Focuses on preventing or reduces alcohol and substance abuse.in teens with FASD. Provides alcohol education, and teaches coping skills and adaptive responses to alcohol-related social pressure.	Adolescence	Univers ity clinic	Trained therapist	Teen and parent groups	6 weeks	More likely to cut down or abstain from drinking, engaged in less risky drinking, fewer negative consequences from drinking, increased expectancies of negative consequences of alcohol use, no changes in positive expectancies of alcohol use	O'Connor (2014)

Nutrition and Medication

Choline	Choline supplementation pre- or post-natally.	Prenatally- 10 years	Home	Medical doctor or child psychiatrist	Administration of supplement as prescribed	Frequency and duration as prescribed	Improved explicit memory in younger children; no specific choline effects for infants (prenatal administration) or children 5-10 years (postnatal)	Wozniak et al., 2015; Kable, Coles, Keen et al., 2015; Nguyen, 2015
ADHD medication	Medication prescribed to target symptoms consistent with ADHD. Type and dosage of medication determined by physician, including stimulants, dexamphetamine, and methylphenidate.	5-14 years	Home	Medical doctor or child psychiatrist	Administration of medication as prescribed	Frequency and duration as prescribed	Improved hyperactivity/impulsi vity and opposition/defiance, no change in inattention	Doig et al., 2008; Oesterheld et al., 1998; O'Malley et al., 2000; Snyder et al., 1997
Neuroleptics	Prescription of neuroleptics with dosage determined by family doctor in combination with social skills training	5-11 years	Clinic	Medical doctor or child psychiatrist and doctoral level clinical psychologist	Child group and parent sessions combined with medication	12 weeks, once a week, 90 minutes	Improved self- control, assertion, and problem behaviors (parent and teacher report), those prescribed stimulants showed no change or deteriorated	Frankel et al., 2006

Parent Education and Training

Because good quality caregiving and a stable, nurturing home environment are protective against secondary conditions in children with FASD (Streissguth et al., 1996), parent training and support programs are a logical approach for helping parents to better understand and respond to the neurodevelopmental disabilities of their children. Interventions in the parent education and training domain focus on the caregiver-child relationship, psychoeducation, positive behavior support, and/or mentoring and accessing community resources.

Parent-Child Assistance Program (P-CAP). The Parent-Child Assistance Program (P-CAP) was developed in Seattle, WA to provide women with alcohol and substance use problems support in connecting to community resources, coordinating services, and ensuring a safe environment for their children. Women work with a paraprofessional advocate case manager for three years. Services can be delivered in the home. Although research has documented positive maternal outcomes as a result of P-CAP, no group differences were found on children's performance on the Bayley Scales of Infant Development at age 3 (Kartin et al., 2002).

Breaking the Cycle (BTC). Relationship-focused dyadic interventions applied in infancy and early childhood have been effective at improving family functioning and preventing adverse outcomes in children in other high-risk populations (e.g. Cicchetti, Rogosch, & Toth, 2006; Bernard et al., 2012). Children with FASD are at risk for having insecure attachments with caregivers, and preliminary studies suggest more responsive caregiving is associated with lower risk for depression in childhood (O'Connor, 2014) and improved neurobehavioral functioning (Motz et al., 2011). The Breaking the Cycle program was developed in Toronto, Canada and targets the parent-child relationship in substance-abusing mothers and their young children. It is a single access model that coordinates comprehensive services, including home visitation and

outreach. This program has been studied in community settings and research suggests it is successful in decreasing maternal substance use, improving maternal mental health, increasing relationship capacity, and improving child outcomes (Koren, 2013).

Parent training workshops. Psychoeducation training programs for families raising children with FASD have focused on effective behavior management strategies and advocacy tools. Various delivery formats have been developed, including online, in written packets, or through in-person workshops, all of which have been rated as satisfactory by families (Kable et al., 2012). This flexibility in format allows training to take place in different settings, depending on the resources available; online programs and information packets can be utilized at home, whereas workshops can take place at clinics or in communities. Multiple formats also allow for flexibility in duration and in requirements for a trained therapist. Several research trials in Atlanta, GA have utilized these materials and have found increases in parent knowledge and improvements in child behavioral functioning in children 3-10 years old (Coles, Kable, & Taddeo, 2009; Kable & Taddeo, 2007; Kable et al., 2012; Bertrand, 2009: study 4). Some variability in outcomes was found based on format, with the in-person workshop format producing somewhat better results relative to the online format (Kable et al., 2012).

Coaching Families (CF) program. The Coaching Families (CF) program works to educate families about FASD, help access resources, and assist in successful advocacy. While psychoeducation is a component of this intervention, it also includes a mentor who works with individual families to help them achieve their goals. This intervention was developed for families raising children from less than a year to 23 years old. Mentors have at least two years of post-secondary education and two years of experience in the field. Retrospective, pre-post evaluation

of the program in Alberta, Canada found decreases in identified family needs, increased goal attainment, and decreased caregiver stress (Leenaars et al., 2012).

Parent-Child Interaction Therapy (PCIT). Parent-Child Interaction Therapy (PCIT) is an evidence-based treatment that has been applied with a number of populations. It consists of in vivo parent coaching to improve the parent-child relationship, increase the child's social skills, reduce problem behavior, and help parents create a positive discipline program. A group-based adaptation of PCIT has been tested in one study in Norman, OK with children (3-7 years old) with FASD relative to a psychoeducation and support group meeting at similar frequency. Attrition was relatively high in this study (54%) and the two groups did not differ significantly on any outcomes. However, both groups showed some improvements in child behavior problems and parenting stress (Bertrand, 2009: study 4).

Families Moving Forward (FMF). Families Moving Forward (FMF) aims to reduce child problem behavior and improve child and family functioning by modifying parenting attitudes and responses toward challenging behavior. A trained mental health provider coaches caregivers at home in 90-minute sessions every other week for 9-11 months. In a randomized controlled trial in Seattle, WA with families raising children (5-11 years old) with FASD, FMF improved caregiver self-efficacy and self-care, met family needs, and reduced child problem behavior relative to treatment as usual (Bertrand, 2009: study 5). A study is currently underway evaluating FMF in combination with a child socioemotional skills program as compared to treatment as usual.

Parent-Child Assistance Program (P-CAP) for Adults with FASD. Research finds adults with FASD have elevated rates of substance use and out-of-home placement for their children (Streissguth et al., 1996). P-CAP (described above) has been adapted for women with

FASD. Adaptations included education and training in the effects of prenatal alcohol exposure on brain and behavior and management issues of adults with FASD, how to facilitate the diagnostic process, and weekly case consultation. Preliminary findings after 1 year in Seattle, WA suggest improved outcomes including reduced drug and alcohol use, increased utilization of medical and mental health case services, greater use of contraception, and acquisition of stable housing (Grant et al., 2004).

Step-by-Step Program. The Step-by-Step program is another program for adults with FASD based loosely on the P-CAP program. In this intervention, mentors help parents with FASD meet family needs and achieve individualized goals regarding housing, addiction treatment, financial supports, and parenting. This one-on-one mentoring takes place over three years and can be done in the home. Retrospective pre-post evaluation of this program in Alberta, Canada found reductions in identified family needs and increases in goal attainment (Denys et al., 2009).

Attention and Self-Regulation

Children with FASD often struggle with deficits in attention and self-regulation (Kable, O'Connor, et al., 2015). This has led researchers like Kodituwakku (2011) to put forth guidelines for future research and intervention development focusing on this domain. A number of intervention programs have been developed to address this area of functioning.

Pay Attention! Program. The effects of the Pay Attention! Program has been studied with Labrador Inuit children (ages 6 to 11) with FASD (Vernescu, 2009). The Pay Attention program targets visual and auditory sustained attention through presentation and training on activities graded in difficulty presented by the interventionist. The program is delivered in 12, 30-minute sessions administered daily over 3 weeks. Relative to a contact control condition,

children in the Pay Attention group, showed greater improvements in sustained attention.

Generalized effects were also seen on measures of selective and alternating attention, as well as on a measure of nonverbal reasoning. No group differences were seen on teacher report measures (Vernescu, 2009).

Computerized Progressive Attention Training (CPAT). Computerized Progressive Attention Training (CPAT) is a computer program that works with children on four skills related to attention. Children simultaneously receive individual support and coaching to aid in generalizing what they learn in the game. This intervention takes place four times a week in 30-minute sessions, totaling 16 hours of training. Sessions are conducted in school and training is done by a teacher or trained assistant with secondary education. It has been tested in children with FASD ages 8-15 years old in British Columbia, Canada. Data from a small pilot study suggests CPAT leads to improvements in sustained and selective attention, spatial working memory, and reading and math fluency (Kerns et al., 2010).

Rehearsal training interventions. Rehearsal training has been effective in improving working memory in typically developing populations and populations with other developmental disabilities (Turley-Ames & Whitfield, 2003). In Alberta, Canada, teaching children a rehearsal strategy over two sessions increased their memory for numbers (Loomes et al., 2008), suggesting this strategy may be helpful for enhancing academic performance in school settings.

Cognitive Control Therapy (CCT). Cognitive Control Therapy (CCT) teaches children how to think and engage in self-regulation and self-observation. It has been tested with children with FASD from ages 8-9 years old in a school setting in South Africa. CCT is administered individually with an experienced and trained therapist over the school year in weekly hour-long sessions. Results from a small pilot study suggest it leads to improved behavior and adaptive

functioning in the classroom. However, no effects in meta-cognitive skills or neuropsychological functioning were detected (Riley et al., 2003).

GoFAR. Using a computer game, parent training, and behavioral analogue therapy sessions, GoFAR teaches children metacognitive and affective control strategies to improve adaptive functioning. This intervention was developed for children with FASD (5-10 years old) and is delivered in a total of ten hour-long sessions. It takes place in a clinic with a trained therapist and the sessions are one-on-one with the child. Preliminary research in Atlanta, GA suggests GoFAR is effective in decreasing child disruptive behavior (Coles et al., 2015).

Alert Program for Self-Regulation. Originally developed by occupational therapists for children will self-regulation difficulties, the Alert program utilizes sensory integration and cognitive strategies to help children monitor and modify their behavior (Williams & Shelleberger, 1996). This 12-week program is typically delivered by a trained clinician in one-on-one sessions with the child. This program has been evaluated in a study with children with FASD (ages 6 to 12) in Toronto, Ontario. Improvements were found in inhibition naming, affect recognition, and parent-reported behavioral regulation in a delayed-waitlist controlled trial (Nash et al., 2015). In addition, recent research has found that the Alert program is associated with increases in grey matter in the brain in critical regions for self-regulation (Soh et al., 2015).

Parents and Children Together (PACT). The Parents and Children Together (PACT) program was developed in Chicago, IL and integrates components of the Alert Program with strategies that are effective for children with traumatic brain injury. It is a group-based program for children with FASD (ages 6 to 12) and their parents. In PACT, children and parents meet in concurrent groups for 12 weeks. PACT is implemented in a clinic setting with licensed mental

Adaptive Functioning

health specialists. Research suggests PACT is effective in improving executive functioning and child emotional problem-solving, per parent report (Bertrand, 2009: Study 3; Wells et al., 2012).

Research has demonstrated that children with FASD have significant impairments in adaptive functioning (Ase et al., 2012; Crocker et al., 2009). As a result, a number of important interventions have been developed in this domain. Targeted areas of adaptive functioning include safety awareness, social functioning, academic achievement, and substance use prevention.

Fire and street safety virtual training. Virtual worlds have been used to teach children with FASD fire and street safety skills. In a computer game developed in Atlanta, GA, an animated dog teaches children safety skills in small, incremental steps and restricts incorrect or dangerous movements. The game can be played with children from 4-10 years old until they reach mastery, which usually occurs in less than 30 minutes. It is versatile in that it can be played in a variety of settings with any adult supervising the child to ensure he or she understands the content. Research has shown that this program improves knowledge and that children are able to successfully generalize that knowledge to behavioral settings (Padgett et al., 2006; Coles et al., 2007).

Good Buddies. Originally known as the Children's Friendship Training program (Frankel & Myatt, 2003), Good Buddies was adapted for children with FASD in Los Angeles, CA taking into consideration their neurodevelopmental and behavioral needs (Laugeson et al., 2007). Children from 6-12 years old learn targeted social and friendship skills in groups lead by a doctoral level psychologist, which occurs over 12 weeks in a clinic setting. A concurrent caregiver group teaches parents how to support their children's friendships and social skills. Good Buddies has been associated with a number of positive outcomes, including improved use

and knowledge of social skills, decreased hostile attributions in peer entry situations, fewer behavior problems, and improved self-concepts (Bertrand, 2009: Study 1; Frankel et al., 2006; Keil et al., 2010; O'Connor et al., 2006; O'Connor et al., 2012). Children achieved better outcomes if they were also taking neuroleptic medication (Frankel et al., 2006). The program proved to be equally effective in community settings for children with and without FASD (O'Connor et al., 2012).

Kid's Club. Researchers in Seattle, WA developed Kid's Club, a community-based social skills program for children age 7-12 years that accommodates the sensory needs of children with FASD, provides structure and consistency, and involves caregivers. Concurrent parent and child sessions take place weekly for 90-minute sessions over 7 weeks. Master's level occupational therapists lead groups. Pre-post testing indicates gains in child social skills, per parent report (Sparks-Keeney et al., 2011).

Literacy and Language Training (LLT). Children with FASD often experience difficulties with academic achievement (Howell et al., 2006; Goldschmidt et al., 1996). The Literacy and Language Training (LLT) program focuses on language skills, phonological awareness, and literacy training to help improve academic performance. This intervention was developed in South Africa for the school setting with children 9-10 years old in groups led by a speech and language therapist. Meetings take place twice a week for 30 minutes over the school year. Relative to children with FASD who did not receive LLT, research suggests that LLT leads to greater gains in specific categories of language and literacy, although no group differences were found on the general scholastic achievement battery (Adnams et al., 2007).

Math Interactive Learning Experience (MILE). In a similar attempt to bolster academic achievement, the Math and Interactive Learning Experience (MILE), developed in

Atlanta, GA, uses individualized tutoring, at home activities, and parent instruction to improve behavior and math functioning. Parent workshops, case management, and consultation also serve to support each child's readiness to learn. MILE can take place in clinics or community sites and consists of 6 weeks of sessions with trained instructors. In children 3-10 years old, MILE has been associated with gains in math functioning post-intervention and at follow-up, with no differences in outcome among settings (i.e., university clinic vs. community settings) (Kable et al., 2015; Coles et al., 2009; Taddeo et al., 2015).

Project Step-Up. Adolescents with FASD are at increased risk for alcohol use disorders above and beyond their family history of alcoholism (Alati et al., 2006; Baer et al., 2003). Project Step-Up was designed for adolescents with FASD and their parents with the goal of preventing or reducing alcohol and substance abuse. Teen and parent groups are delivered concurrently and occur weekly for six weeks. Intervention content focuses on providing alcohol education, fostering skills to cope with stress, and teaching adaptive responses to alcohol-related social pressures. Preliminary results from this trial in Los Angeles, CA found that Project Step-Up is associated with a greater likelihood of cutting down or abstaining from drinking, engagement in less risky drinking behavior, fewer negative consequences from drinking, and increased expectancies of negative consequences from alcohol use (O'Connor, 2014).

Nutrition and Medication

Although there are no specific biological treatments for FASD, preliminary studies have begun to garner evidence that certain nutritional supplements and medications are associated with behavioral improvements in this population. Choline, stimulants, and neuroleptics are a few kinds of biologic treatments that have been tested in this population.

INTERNATIONAL FASD INTERVENTIONS

Choline. Research in animal models documenting improvements in cognitive and motor functioning after pre- or post-natal administration of choline (Ryan, Williams, & Thomas, 2008; Thomas et al., 2009) has led researchers to examine the effect of choline supplements in humans. In a relatively large study in Ukraine, the effects of prenatal micronutrient supplementation (with or without supplemental choline) on cognitive and motor development were studied in 6-month old infants. Micronutrient supplementation had a protective effect on cognitive, but not motor, development. No significant effects were found with the addition of choline supplementation (Kable, Coles, Keen et al., 2015). Post-natal supplementation of choline has also been tested in two trials. In the first trial, children 2-5 years old with FASD were administered 500 mg of choline daily in a powdered, fruit flavored drink mix over a 9-month period. Preliminary outcomes indicate choline supplements are associated with improved explicit memory, but only in younger children, suggesting a critical developmental period for this intervention (Wozniak et al., 2015). A trial with older children (ages 5-10 years old) with FASD over a 6-week period did not find any significant cognitive improvements over placebo during this short trial, supporting Wozniak and colleagues' (2015) developmental finding (Nguyen, 2015). Research also suggests weight adjusted rather than fixed dosages may have better memory outcomes (Wozniak et al., 2015).

ADHD medication. Many children with FASD are comorbidly diagnosed with ADHD (Burd et al., 2003) and are often prescribed medications for ADHD symptoms. Several small studies have examined the efficacy of ADHD medications for children with FASD (see Peadon & Elliot, 2010). A pilot study of methylphenidate in Native American children in South Dakota found the medication decreased hyperactivity and impulsivity but not inattention (Oesterheld et al., 1998). However, a retrospective study suggests children with FASD and ADHD

preferentially respond to dexamphetamine over methylphenidate (O'Malley et al., 2000). Another small study found regular stimulants improved hyperactivity symptoms but not attention (Snyder et al., 1997). This outcome was replicated in a retrospective chart review study, which found that ADHD medication was associated with improved hyperactivity/impulsivity and opposition/defiance symptoms, but not with changes in attention (Doig et al., 2008).

Neuroleptics. In a study examining the moderating effects of type of medication on outcomes of children participating in the Good Buddies program, neuroleptics were associated with improved outcomes. These medications were prescribed to children by family physicians outside of the research trial. Children taking neuroleptic medications in Los Angeles, CA demonstrated greater improvements in self-control, assertion, and problem behaviors per parent and teacher report in comparison to children taking other medications or no medications; children taking stimulants showed no change or their performance deteriorated over time on average relative to other children (Frankel et al., 2006).

Addressing Cultural Barriers to Implementation

Developmental and mental health services are embedded in multiple systems of health and human services, making input from stakeholders at multiple levels an essential part of implementation efforts (Backer, David, & Soucy, 1995; Ferlie & Shortell, 2001; Green & Aarons, 2011). Research has found that successful implementation accounts for factors relating to the target group (such as knowledge and attitudes relating to the presenting problem) and factors relating to the system (such as capacity, resources, and service abilities; Grol & Wensing, 2004; Davis, Thomson, Oxma, & Haynes, 1995; Solomon, Hashimoto, Daltroy, & Liang, 1998). In order to understand what elements of FASD interventions specifically may be relevant to local

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stakeholders, it is important to first understand cultural barriers to addressing FASD (see Table 2 for a summary).

Table 2

Barriers to Addressing FASD

Lack of knowledge about FASD

Community

Parents

Teachers

Providers

Delayed diagnosis

Untrained providers

Scarcity of clinics

Clinician attitudes

Qualifying for services

FASD as an established category in developmental disability policy

FASD as an established category in educational systems

Availability of services

Presence of local programs

Insurance coverage

Availability of evidence-based interventions

Implementation of services

Inflexible programs don't address individual differences

Uncoordinated services

Maintenance of services

Lack of lifelong support

Skepticism about risks of alcohol use in pregnancy

Documentation of alcohol use in pregnancy

Identifying and targeting high risk groups

Identification of risk factors

Cultural attitudes

SES

Alcohol dependency prior to pregnancy

Establishment of prevalence rates

Inconsistencies in type of data reported

Different diagnostic systems

Stigma

Lack of awareness

Reluctance to diagnose

Reluctance to discuss drinking with physicians

Cultural Barriers to Addressing FASD

In the United States, Petrenko and colleagues (2014) conducted a qualitative study to assess systems-level barriers to the prevention of secondary conditions in individuals with FASD. They found that a pervasive lack of knowledge about FASD was the overarching obstacle, contributing to delayed diagnosis, unavailable services, and challenges qualifying for, implementing, and maintaining services. Limited or absent knowledge about FASD can lead parents, teachers, and providers to overlook or misdiagnose FASD. Correct diagnosis is important for interventions because treatments targeting other conditions may miss the true etiology of the challenging behavior. Lack of clinician knowledge and entrenched clinician attitudes extend internationally as well. In Australia, only 12 percent of health professionals and 19 percent of pediatricians knew the diagnostic criteria for FAS, and 50-73 percent of health professionals found the diagnosis stigmatizing when surveyed (Elliott et al., 2006; Payne et al., 2005). Further, diagnostic clinics are concentrated in North America, and even still are not available in every state or province (Peadon et al., 2008).

Petrenko and colleagues (2014) also found that qualifying for services can be a major obstacle because FASD is not an established category within developmental disabilities or educational systems in the US. Even if children do qualify, FASD-informed services are often locally unavailable. Insurance coverage or other sources of funding can be an additional barrier to accessing any services that are available. In cases where children and families are able to access services, the lack of flexibility to address the range of strengths and weaknesses among these individuals can be frustrating for those involved. Coordination of services can also be overwhelming for families. Maintenance of services is a further obstacle, since providers often

remove services when children improve, but often individuals with FASD need continued supports and services to maintain gains. Although the systems-levels barriers identified in this study were found in the context of a North American city, many of them likely apply to international contexts as well.

Elliott (2013) highlighted additional global challenges to addressing FASD. Skepticism about FASD is a barrier created by conflicting evidence regarding whether alcohol is in fact damaging to a fetus (Flak et al., 2014; Richardson et al., 2014; Sowell, Charness, & Riley, 2014). Challenges documenting alcohol use in pregnancy constitute another barrier. This documentation is important for identifying high-risk groups and targeting them for treatment and prevention. Understanding risk factors can help researchers implement more targeted interventions. For example, a study by Peadon and colleagues (2011) found that education alone is not effective for preventing drinking during pregnancy; community attitudes about alcohol also need to change. Socioeconomic factors and alcohol dependency prior to pregnancy may confer additional risk and warrant specific programming.

Inconsistencies in establishing FASD prevalence also impede progress toward addressing FASD (Elliott, 2013). This data is essential for garnering government support and recognition of FASD as a problem, as well as for convincing funders for their support and resources. Establishing prevalence rates presents such a challenge because diagnosis is complex, time consuming, and costly. Further, certain data indicates prevalence of FAS and other data indicates prevalence of FASD, while some statistics may be birth prevalence, others may be population prevalence, and still others may be incidence rates. This makes it difficult to consolidate information across contexts. Part of the challenge establishing prevalence rates is also due to the fact that there are currently five diagnostic systems in use: New Canadian Diagnostic Guidelines

for FASD (Cook et al., 2015), 4-digit code (Astley & Clarren, 2000), Institute of Medicine (IOM; Hoyme et al., 2005), National Task Force/CDC (Bertrand et al., 2004, 2005), and DSM-5 (Kable, O'Connor, et al., 2015). These systems all focus on the same features pertaining to face, growth, brain, and alcohol exposure, but the terminology and cutoffs differ (Riley et al., 2011). This adds complication and confusion to diagnosis. In addition, differences in facial features by race and ethnicity complicate facial diagnostic criteria. While criteria do not differ among races and ethnicities, what is considered normal variation does differ. Unfortunately, normative data for physical measurements are not available in many countries and regions, and the guides that are in use were developed from a subset of races and ethnicities.

Stigma regarding alcohol use in pregnancy and the diagnosis of FASD is complex in the way it interacts with cultural barriers. Certain cultural attitudes show little stigma towards drinking in pregnancy, which presents a significant risk factor for FASD. In rural South Africa, for example, many mothers reportedly had little knowledge of FASD, and therefore drinking during pregnancy was not as stigmatized (May et al., 2005). However, lower levels of stigma can also be positive in that they can increase women's comfort level discussing their drinking before and during pregnancy. Higher stigma contexts, such as in the US, often have difficulties reliably assessing maternal drinking in pregnancy. A further challenge relating to stigma is that clinicians can be hesitant to label a child with FASD for fear of the social consequences for both the child and the mother (Elliott, 2006).

Qualitative studies on cultural barriers and risk factors unique to each country would add valuable information to the literature. In Russia, for example, Balachova and colleagues (2014) identified mothers' and clinicians' knowledge of FASD as important factors in a woman's choice to drink during pregnancy. Younger women also valued the knowledge and opinions of

husbands, mothers, friends, and coworkers, suggesting it is important to educate these individuals as well. This study provides important information about what risk factors are most relevant to Russian women, and therefore effectively informs prevention efforts. More studies like this would allow researchers to tailor their efforts to specific cultural risk factors and effectively address barriers to intervention.

Cultural Liaisons and Stakeholders

Given the abundance of potential barriers to implementation, both general and culturally specific, it is important for researchers to include cultural liaisons on their implementation teams who can help recognize and address cultural differences. These individuals are sometimes called purveyors (Fixsen et al., 2005) and their main responsibility is to assess and help to develop site readiness for implementation. This role sometimes involves promoting administrative or system changes to make the environment more hospitable for the intervention. In some cases, purveyors' responsibilities require developing local or state infrastructure (Edwards et al., 2001; Slavin & Madden, 1999). Cultural liaisons can also be lay therapists who are trained in the intervention model but who also serve as cultural experts to advise researchers when technique modifications may be necessary (Murray, Dorsey, Bolton, Jordans, Rahman, Bass, et al., 2011).

Purveyors hold an important role on the implementation team, which includes multiple levels of local stakeholders. The kind of multidisciplinary team recommended for the complex needs of individuals with FASD may include: a) a physician for diagnosis, medication, and health needs, b) a psychologist for diagnosis, development, and mental health, c) speech, occupational, and physical therapists for developmental services, sensory needs, and social communication, d) a family advocate, and e) a coordinator for case management (Chudley et al., 2005). Purveyors can help by communicating with the stakeholders to educate them about the

components of the programs, the changes that would need to take place in the implementation process, and the fit with local needs and resources (Slavin & Madden, 1999).

Considering the goals and activities of local individuals involved in the project will improve their buy-in, commitment to, and understanding of the intervention. Buy-in from local stakeholders is beneficial in a number of ways. It may provide resources or referrals for areas not covered by the program. It may also facilitate sustainability because stakeholders can help integrate the program with the government and existing organizations like clinics. Further, local stakeholders have a better understanding of what resources, both human and material, will be necessary to run the program in the given environment. Stakeholders should be involved at all aspects of the implementation process, including planning, monitoring, and follow-up.

An important first step in the implementation process is engaging the stakeholders in a conversation to select an intervention that fits best with the cultural context. A number of intervention components may be important for the team to consider. For example, format of the intervention may be a deciding factor. Some interventions are held in groups, while others work individually. Some include parents and other family members, and others work with the children alone. The setting of the intervention is another important detail to consider. Does the treatment take place at school, at a clinic, or at home? Would transportation or childcare for other siblings be prohibitive? The type of counselor may also be relevant. The gender of the counselor and his or her level of expertise may be influenced by culture. Finally, the frequency and duration of the sessions may be an element to take into account because it may place demands on clinicians and families that make the program unsustainable.

During the process of preparing and implementing the interventions, certain adaptations may need to be made to make the intervention more culturally consistent for the local population

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or fit better within existing systems. This process of adaptation involves modifying techniques in a culturally sensitive way while maintaining fidelity to the core intervention model (Kendall & Beidas, 2007). This has been done with evidence-based interventions outside of FASD. For example, Trauma-Focused Cognitive Behavioral Therapy (TF-CBT) was modified and implemented in Zambia (Murray et al., 2013). In this project, the researchers made adaptations by training lay counselors, using simplified language (e.g. changing "affect modulation" to "talking about feelings"), sensitively addressing culturally taboo topics (e.g. sexual abuse), providing culturally relevant examples, and using local metaphors. Similar kinds of modifications could be applied to FASD interventions. A modification that would be important in the context of FASD is partnership with a diagnostic clinic. This diagnostic component is important for continuing referrals and keeping interventions sustainable. Further, having treatment and support readily available helps to convince community members of the importance of diagnosis.

The continuous cultural exchange between the research team and local organization is a critical part of this process. In implementing evidence-based interventions, researchers have found that interpersonal contact between organizations and communities is essential for a program to change behavior (Palinkas, Allred, & Landsverk, 2005; Rogers, 2003). Palinkas and colleagues (2009) used two case studies of evidence-based interventions implemented in the United States to illustrate the components of successful cultural exchange. They found this exchange involved both resources and knowledge. In the resource exchange, the researchers provided funding, monitoring, prestige, staff recruitment, and opportunities for staff training and supervision. The users of the treatment provided access to participants and assistance with solving problems presented by the setting. In the knowledge exchange, the researchers provided

an evidence-based approach and gathered data on the program's effectiveness. Local clinicians provided knowledge of the needs of the population and the most culturally effective ways to meet those needs. Palinkas and colleagues (2009) also identified key communication dynamics between the research team and local stakeholders associated with effective implementation. These dynamics include possessing similar goals, sharing a sense of teamwork and shared control, having an element of perceived reciprocity, and communicating frequently. By working with multiple levels of local stakeholders and using purveyors as cultural liaisons, researchers can create open communication and effective exchanges with the community. This sets the stage for successfully addressing cultural barriers and implementing FASD interventions.

Summary and Recommendations

FASD is present across countries and cultures. Prevalence rates range from 2 to 20 percent worldwide (May et al., 2012, 2014; Urban et al., 2008), and may continue to grow in the coming years (Popova et al., 2014). In order to support children and families around the world, researchers must work to disseminate and implement evidence-based interventions. However, each cultural context presents unique elements and barriers to the implementation process. For this reason, it is important for researchers to collaborate with local stakeholders and use cultural liaisons to help bridge the gap between research and practice. An important first step in this process is knowing what FASD interventions exist as options. The next step is being aware of cultural factors that will influence implementation. Armed with knowledge in these two areas, researchers and stakeholders can work together to make the best decision for the children and families in that community and work to overcome cultural barriers that impede progress.

In order to effectively embark on this process of international implementation, research must continue in a number of areas. Researchers must keep building the evidence base for FASD

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interventions. The more data that is available on outcomes and mechanisms of change, the more educated decisions can be made about what program will best meet the needs of the population. Part of this process involves continuing to publish the results of studies that have nonsignificant findings or involve less rigorously designed community trials. This will allow researchers to compile data and form a more comprehensive understanding of available interventions. Also, researchers must continue to develop interventions that reach across the lifespan. Many interventions that currently exist target middle childhood, leaving individuals in early childhood, adolescence, and adulthood under-supported. Existing interventions should also continue to be replicated by different investigators and in different regions of the world.

More research must also be done on cultural barriers to addressing FASD. Petrenko and colleagues (2014) and Balachova and colleagues (2014) have done important work toward understanding the unique perspectives of individuals within their communities. Ceccanti and colleagues (2007) conducted similar work in Italy in order to more fully understand the Italian phenotype of FASD and the drinking habits of Italian women for the purposes of better targeting mechanisms for prevention and intervention. In Korea, Lee and colleagues (2010) also investigated prevalence of drinking during pregnancy and related risk factors specific to their population. Systematic investigation of cultural variables is key for successfully generalizing research on FASD.

Although there is still no gold standard for implementation research, collaboration is a universal element. Local stakeholders should be engaged across all system levels. Cultural liaisons should help bring together researchers and the team of local providers. Partnerships should extend across countries and share their experiences and expertise with one another. Open communication on local, national, and international levels is inherent to success.

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Given that a number of barriers to addressing FASD have already been identified, work can begin toward removing those obstacles. Priority should be given to spreading awareness of FASD. This can be done through public health campaigns, multimedia, and education across professions. More diagnostic clinics should be opened, more screenings should be done, and more professionals should be trained in order to improve diagnosis. Systems should be revised to include FASD and help individuals and families qualify for services. To make services more available, dissemination should be increased and programs should be integrated into existing systems of care. Coordination of services across systems should be improved for easier access. More priority should be given to funding allocated for FASD program evaluation. Research should be done to establish and clarify prevalence rates, and alcohol use in pregnancy should be more thoroughly documented. This information is critical for gaining funding and policy change. For a summary of recommendations, see Table 3.

Table 3

Recommendations

Be aware of intervention options

Research mechanisms of change Publish all results Develop interventions across the lifespan

Replicate existing interventions

Replicate existing intervention

Consider culture

Conduct qualitative research on risk factors and cultural barriers

Work collaboratively

Include stakeholders

Use purveyors as cultural liaisons

Partner across countries

Address barriers

Spread awareness of FASD

Improve diagnostic capacity

Revise systems to include FASD

Disseminate evidence-based interventions

Integrate programs into existing systems

Coordinate services

Fund intervention evaluations
Establish prevalence rates
Document alcohol use in pregnancy

As FASD gains recognition worldwide and research on prevalence rates begin to emphasize the severity of prenatal exposure to alcohol, researchers should work together to provide services to individuals and families in need. Dissemination and implementation of empirically supported FASD interventions is an important way to make services more available. Collaboration with cultural experts and local stakeholders helps make the implementation process more effective and sustainable. By recognizing and addressing cultural barriers to FASD, researchers can respond to calls to action by colleagues and international organizations alike to improve the capacity for nations worldwide to treat and care for families and individuals with FASD.

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