Development of Life Skills: Education, Parenting, and Family Mentoring

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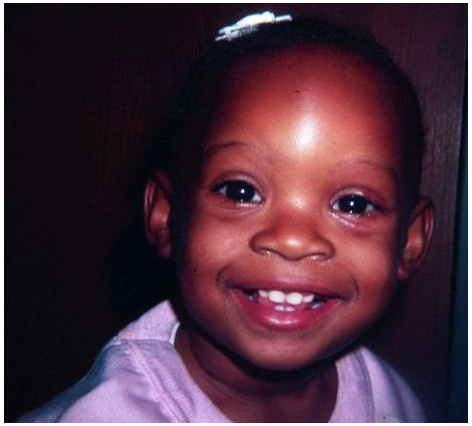
FASD Intervention Research



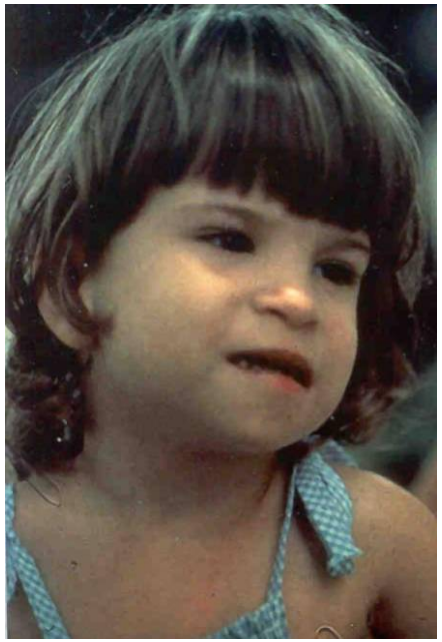
The teratogenic effects of prenatal alcohol exposure were described in the 1970's.

In 2009, investigation into methods for improving outcomes for affected individuals and families is in its infancy.

People with FASD may have problems in the following areas through out their lives:

- **Physical/ Health/Motor**
- **Developmental/ Cognitive**
- **Behavioral/ Social**
- **Academic/ Vocational**

Background



- FASD unrecognized in most settings.
- Developmental, educational and behavior problems ascribed to other causes.
- Diagnoses and treatments nonspecific and often fragmentary.
- Due to etiology (“brain damage”) children considered “untreatable”.
- Victims often have no advocate.

Background

- Treatment has been dependent on what is generally available based on local laws and regulations.
- No support for FASD specific treatment programs or evidence based interventions.
- FASD is a life-long disability. Life- - birth through all of adulthood.

There are many “myths” that interfere with treatment of FASD

- “You can’t identify it during infancy”
- Only (*insert negative stereotype here*) have FAS and you can’t work with them!”
- “Children with FASD can’t learn.”
- “They don’t generalize.”
- “Behavior modification doesn’t work.”
- “They all have ADHD.”

Intervention and Treatment

“Standard” Therapeutic Interventions for **Children**

- **Early Diagnosis**
- **Early Intervention**
- **Therapeutic interventions for specific deficits (OT, PT,SLT)**
- **Behavioral management, psychotherapy, family therapies**
- **Medical interventions**
- **Educational Interventions and programs**

Why Diagnosis?
Is there anything "special" about alcohol effects

- **Or, Won't the "usual" diagnoses and treatments work?**
  - **Strong evidence for neurodevelopmental damage affecting cognitive skills and behavior.**
  - **The diagnosis "organizes" observations by professionals and expectations for child and family.**
  - **Children are likely to have multiple risk factors that need to be taken into account.**
  - **Neurodevelopmental deficits and environmental risk lead to significant secondary disabilities.**
  - **Diagnosis provides guidelines for intervention and treatment.**

Applying the “Standard of Care” to FASD

- **It is always asked, “Is there any thing special about FASD? Don’t they get the services they need from other diagnoses—ID/MR, DD, Learning Disabilities, Behavioral Dx?”**

- **Begging the questions of whether any child is receiving adequate services in this area, how does this work for FASDs?**

What are the standard, recommended treatments for effects of prenatal alcohol exposure?

- **There <u>are</u> none widely used specific to FAS or FASD**
- **There are no universally accepted "standards of care" recommended for FAS/FASD**
- **There is little research on the application of "standard" treatments to alcohol-affected individuals.**

Potential Interventions for Affected Individuals

- **Environmental Change**
- **Skill Building programs**
- **Medications**
- **Therapeutic interventions with Child and Family**
- **Educational programs**
- **Vocational programs/Job Training and Coaching**
- **Substance abuse prevention and treatment**

Skill Building Research (Published)

Author	Skill	Sample	Treatment	Result
Adnams (in Riley et al., 2003)	Metacognition	10 South African Children	Cognitive Control Therapy	No change in cognition; improved behavior
Padgett, Strickland, & Coles, 2006, Coles, et al, 2007	Fire and Street Safety	5 US Children 4-7; 32 US Children 4 to 10	Virtual reality game to teach fire and street safety skills	All children able to perform skills in analog setting; Improved both verbal rule learning and generalization of skills to analog settings. Retained over time
O'Connor et al., 2006; 2009, (March)	Social skills	100 US children 6-12	Bruin Buddies social skills training program	Improved social skills and reduced behavior problems via parental report

Skill Building Research, Cont.

Author	Skill	Sample	Treatment	Result
Kable, Coles, & Taddeo, 2007; Coles, Kable, Taddeo, 2009	Behavior and math functioning	61 US Children between 3-10	MILE: Socio-cognitive habilitation	Improved behavior and math knowledge
Adnams, Kalberg, Kadituwakku, et al. 2007	Academic Skills	65 South African 9-year olds	Classroom Language/ Literacy Intervention	Improved cognitive skills in target areas.
Bertrand, et al (2009)- Overview of 5 Studies	Parenting, Executive Functioning, Math, Social Skills	Multiple samples	Variety of Treatments	Significant improvement in most areas evaluated

Summary of Intervention for FASD

- **Research is very limited in both number and kind of studies. Some areas of intervention remain completely unexplored.**
- **Controlled studies suggest that targeted interventions do improve outcomes.**
- **Affected individuals respond to "standard" treatments that are adapted to their special needs.**
- **Early identification and intervention are of primary importance in prevention of secondary disabilities in behavior, emotional and educational areas.**

Pharmacological Research in Children with FAS(D)

Osterheld et al., 1998

- **Using a randomized double blind cross over study with**
  - **4 Native American Children (5-12)**
- **Condition: Methylphenidate, placebo, and vitamin**
- **Result: No significant differences in measures of attention**

Snyder et al., 2003

- **Using a cross-over design,12 children (6-16) with FAS and AD/HD**
- **Condition: Various stimulant medications**
- **Results: No significant difference on measures of attention;**
- **parent report measure of hyperactivity lower on meds**

What drug treatments work? Summary

- **Few drug treatments have been tested for FASD children (at least formally).**
- **Nevertheless, there is a great deal of medication of alcohol-affected individuals.**
- **Children with FAS do not show a unified psychopharmacologic response.**
- **Providers usually treat individual problems.**
- **The small amount of empirical research available argues against stimulant treatment.**

Summary of Intervention Findings

- Peadon, et al (2009) comments:
  - Successful interventions target specific clinical and neurodevelopmental deficits.
  - The pattern of hyperactivity (or arousal dysregulation) associated with FASD seems to differ from ADHD
  - Health care professionals have a perception that there are no effective interventions

Streissguth, et al. (2004)
The Environment, --Universal Protective Factors in FASD:

- Experiencing a stable, good quality home
  - (10 or more of 12 good qualities from age 8 to 12 years)
  - Staying in a living situation for an average of more than 2.8 years
- Having basic needs met
- Never having experienced violence against oneself
- Early Diagnosis
  - Being diagnosed before age of 6 years
  - Having a diagnosis of FAS (rather than pFAS)
- Receiving Services
  - Having applied for and been eligible for DDD services

Recommendations

Bertrand (for the FASD Intervention Consortium, 2009), notes:

1. Existing methods (can/must) be adapted to special needs of FASD
2. Intervention/treatment can be provided within existing networks
3. Caregiver Involvement necessary
   - Parent as the focus of intervention
   - Improving parental knowledge of FASD
   - Providing “tools” to support behavioral changes
4. Explicit Instruction more effective
   – Children learn new skills better with explicit, focused instruction

FASD: What Next?

1. Early Diagnosis. Doing what is necessary
2. Environmental Stability and Quality Care
3. Focused treatments that take into account specific characteristics of FASD
4. Caregiver involvement
5. Education of educators and health care professionals and providing the tool needed for implementing effective programs
6. Education and Social Service regulations to include FASD as category qualifying for care

References (Selected)

Adnams, CM, et al (2007) Language and literacy outcomes form a pilot intervention study for children with fetal alcohol spectrum disorders in South Africa. Alcohol, 41, 403-14.

Bertrand (for the Interventions for Children with FASDs Research Consortium, 2009) Interventions for children with fetal alcohol spectrum disorders (FASD): Overview of findings for five innovative research projects. Research in Developmental Disabilities 30, 986-1006.

Coles, CD, Kable, JA, & Taddeo, E (2009) Math performance and behavior problems in children affected by prenatal alcohol exposure: Intervention and follow-up. Developmental and Behavioral Pediatrics, 30, 7-15.

Coles, CD, Strickland, DC, Padgett, L, & Bellmoff, L (2007) Games that work: Using computer games to teach alcohol-affected children about fire and street safety. Research in Developmental Disabilities

Kable, JA, Coles, CD. & Taddeo, E (2007) Socio-cognitive habilitation using the math interactive learning experience program for alcohol affected children. Alcoholism: Clinical and Experimental Research 31, 1425-34.

O'Connor, MJ, Frankel, F, et al., (2006) A controlled social skills training for children with fetal alcohol spectrum disorders. Journal of Consulting and Clinical Psychology 74, 639-48.

O'Connor, MJ, Paley, B, et al. (2009,, March) *Lessening the risk of social skill deficits in children exposed to alcohol prenatally: An evidenced based intervention in a community setting.* Presented at 42nd Annual Gatlinburg Conference, New Orleans, LA.

Osterheld, JR, Kofoed, L, et al., (1998) Effectiveness of methylphenidate in Native American children with fetal alcohol syndrome and attention deficit/hyperactivity disorder: A controlled pilot study. Journal of Child and Adolescent Psychopharmacology 8, 39-48.

Peadon, E, Rhys-Jones, B, Bower, C, & Elliott, EJ (2009) Systematic review of interventions for children with Fetal Alcohol Spectrum Disorders. BMC Pediatrics, 9, 35-44.

Premji, S, Benzies, K, Serret, K, & Haydeon, KA (2006) Research based interventions for children and youth with a Fetal Alcohol Spectrum Disorder: Revealing the gap. Child: Care, Health and Development, 33, 387-97.

Snyder, J, Nanson, J, Snyder, R, & Block, G. (1997) A study of stimulant medication in children with FAS. In Streissguth & Kanter (eds) Overcoming and Preventing Secondary Disabilities in Fetal Alcohol Syndrome and Fetal Alcohol Effects. UWA Press, Seattle, WA, 64-77

Streissguth, AP, Bookstein, FL, et al.(2004) Risk factors for adverse life outcome in Fetal Alcohol Syndrome and Fetal Alcohol Effects. Development and Behavioral Pediatrics, 25, 228-38.