

A Consensus Development Conference on Fetal Alcohol Spectrum Disorders (FASD) Across the Life Span

Session on Treatment of FASD

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Conflict of interest

- I have no conflict of interest related to this presentation

IHE Consensus Development Conference on

**Fetal Alcohol Spectrum Disorder
(FASD) – Across the Lifespan**

October 7 to 9, 2009, The Westin Edmonton, Edmonton, Alberta



INSTITUTE OF
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Areas of expertise/perspective

- Child psychiatrist
 - See children with mental health problems with and without prenatal alcohol exposure
- Research interest in the attempts to improve the delivery of evidence-based services to at-risk children



Policy recommendations

1. There is no compelling scientific evidence to support the creation of separate service and treatment tracks for children with FASD and their families
2. Treatment and services required by children with FASD and their families should be delivered within a needs-based service system (not a system driven by a diagnostic category)
3. Emphasis should be placed on strengthening the existing service system to better deliver evidence-based interventions to all children with service needs including those with FASD



Rationale #1 for policy recommendations

- Many difficulties seen in children identified as having FASD in referred clinical populations are similar to difficulties seen in other children with developmental and/or mental health difficulties.
- The overlap far exceeds any unique difficulties.



Rationale #2 for policy recommendations

- The diagnosis of FASD in and of itself provides little to no information as to the specific needs of individual children and hence it does not inform treatment planning.



Diagnostic profile

- E.g., FAS diagnosis (4 digit diagnostic code: 3-4-3-4)
 - Growth: 3 (moderate)
 - Facial Features: 4 (severe)
 - Central Nervous System damage: 3 (probable)
 - Alcohol: 4 (high risk)
- This diagnosis and pattern provides little information to inform treatment planning



Need profile

- In contrast, a profile as follows can be informative for developing a treatment plan
 - E.g., Mary
 - meets criteria for a learning disorder in math
 - demonstrates severe attention deficits
 - Her mother has a major depressive disorder
- Whether or not Mary has FASD does not necessarily alter what one may recommend for Mary & her family



The alcohol exposure

- But what about the treatment implications of alcohol (ab)use of the mother? Well...
 - If the aim is to identify and aid mothers with alcohol abuse problems, one should develop an approach to identify this need (not rely on the manifestation of FASD in an offspring as your primary indicator of maternal need)
 - Also why focus on a single maternal risk behaviour (alcohol use) in order flag potential need for more services and supports? What about flagging and prioritizing maternal mental illness, domestic violence, etc., to inform treatment planning?



Rationale #3 for policy recommendations

- The needs of different children identified as having FASD and their families are so heterogeneous that grouping them together for specific services or treatments is likely to be misguided or at least inefficient.



Rationale #4 for policy recommendations

- All the needs and difficulties manifested by a child with FASD are not just a function of the prenatal alcohol exposure but rather a combination of the many factors that influence child development for all children including many genetic and environmental factors and their interaction.



Importance of other risk factors

Risk factors for child behaviour difficulties at 6-7 years of age within a birth cohort

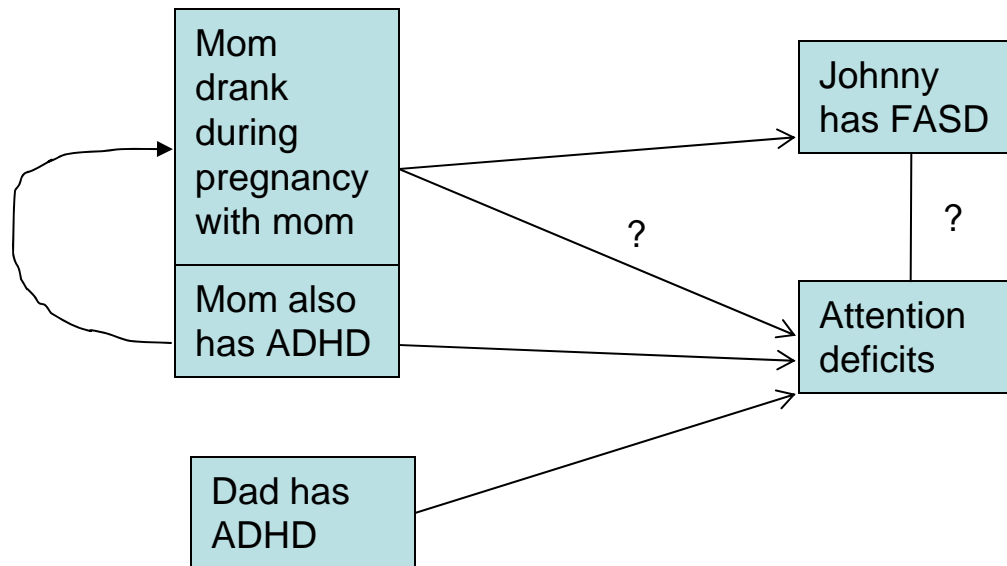
Risk factor	Amount of the outcomes accounted for by the risk factor
Maternal psychopathology	13.0 - 29.1% versus
Prenatal alcohol exposure	0.6 – 1.7%

Sood et al., 2001 Pediatrics



D'Onofrio et al.
(2007)
Archives of
General
Psychiatry

Knopik et al
(2006)
Psychological
Medicine



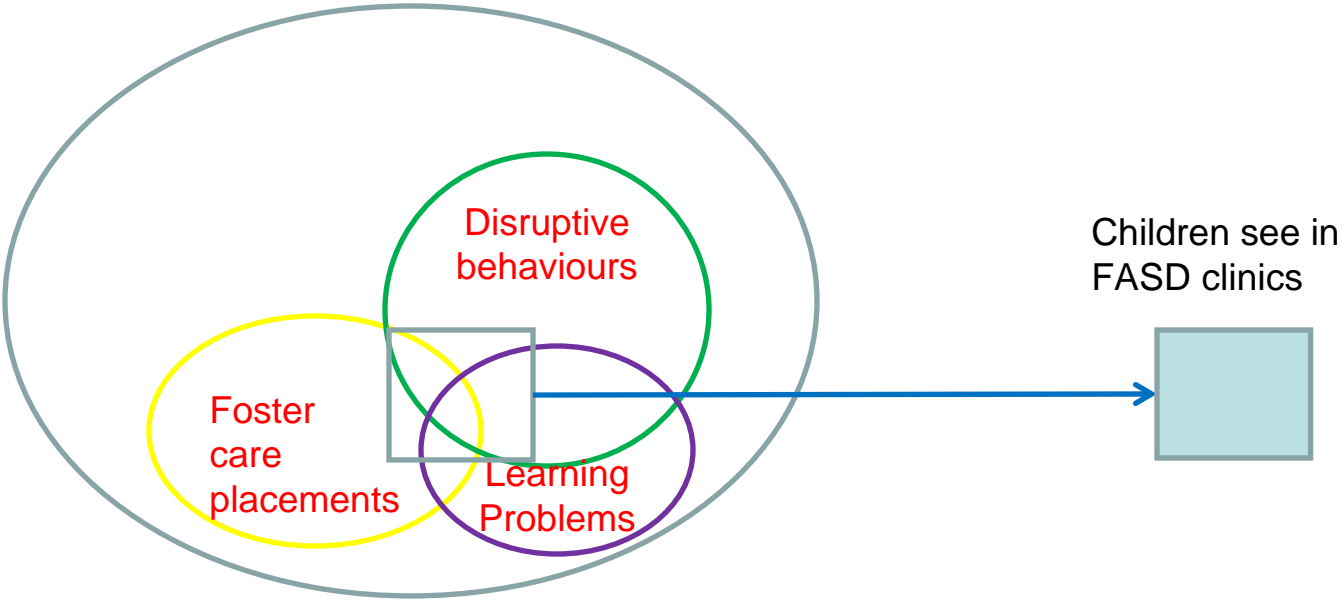
Referral Bias

- Much of our clinical experience with FASD and a number of FASD studies are based on children from specialty clinics where children have been referred.
- Referral bias (Berksonian bias)- spurious or exaggerated associations between conditions (e.g., FASD and behavioural problems) seen in clinic settings secondary to factors that influence referrals to those clinics (e.g., severity of behavioural problems, multi-risk conditions)



Possible conditions contributing to a referral or Berksonian bias

Population of prenatally alcohol exposed children in the community



Example: Prevalence of ADHD & FASD

- Summary of clinic-based studies (Burd et al, 2007)
 - **48%** “ADHD diagnosis”
- A population-based study: (Aragón et al., 2008)

ADHD type	TEACHER		PARENT	
	FASD	Comparison	FASD	Comparison
Inattentive	17%	0%	4%	0%
Hyperactive-Impulsive	0%	4%	0%	0%
Combined	9%	5%	0%	0%



Example: ADHD in referred populations

- Much of the ADHD seen in children with FASD in clinical referred groups is likely not a function of alcohol exposure or FASD but rather the same as for other children with ADHD.
- This does not contradict the scientific evidence that there may be unique attention problems in some children with FASD (e.g., Coles et al. 1997) or overall higher levels of attention problems in this population



Example: ADHD & treatment implications

- Children in FASD clinics who have ADHD ought to be offered evidence-based treatments demonstrated to be effective for ADHD
 - Certain **medications** and/or certain **behavioural modification** approaches



Example: ADHD & Service implications

- Does the current approach to carving out FASD services actually impede access to evidence-based interventions?
 - E.g., Some believe that behavioural modification strategies do not work with children with FASD even though there is no scientific evidence to support this belief. This important treatment option may be withheld due to this belief within a structure that separates out these children based on their FASD diagnosis.



Service Implications

- Interventions may be best delivered by linking children with FASD their families with evidence-based mental health or developmental services aimed at addressing a given child's individual problems or challenges, i.e., based on patterns of need (versus creating a separate service infrastructure driven by a diagnostic category)
- This same rationalization may be argued for other difficulties seen in children with FASD not just for ADHD



Rationale #5 for policy recommendations

- Findings from the very limited number of treatment intervention studies with children with FASD indicate that treatment can lead to improvements
(e.g., Coles et al 2009; O'Connor et al., 2006; Doig et al., 2008; Oesterheld et al., 1998; Peadon et al., 2009- systematic review)
- However, these promising treatment approaches work (or are likely to work) with non-FASD populations that share the difficulty targeted by the treatment (e.g., math disorders, social skill deficits, attentional problems).



Rationale #6 for policy recommendations

- Scientific evidence that would challenge these proposed policy recommendations would be findings identifying treatment approaches that are uniquely or preferential beneficial to FASD children and their families and not other children and their families with overlapping needs.
- No evidence of this type at this time



Conclusion

- There is substantial need for improvement in services for all children with developmental, social, academic and mental difficulties in Alberta.
- Children with FASD represent one group within this larger population and should be served within an expanded evidence-based service system for all at-risk children.
- Emphasis should be placed on improvement of the overall service system and, where appropriate, unique components built in for particular subgroups where there is compelling evidence that these components are uniquely or preferentially effective for the designated subgroups.



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