

FASD Stigma: FASD Key Workers and Walking the Journey With Families

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Presentation Objectives

- Stigma barriers of birth/relative/adoptive/foster parents/caregivers, and individuals diagnosed with FASD.
- FASD stigma and systems (MCFD, mental Health, cultural).
- What caregiver's say helps.
- Creating a prevention message of compassion.

Purpose of Stigma

Mark of disgrace/dishonor (Dictionary).

"Divides, disconnects, Isolates, other (verb),"
Creates "Membership in a weakened group.
Disempowers person and group from their
capacity and self-determination."

Peter W. Choate

Choate, P.W. (2017), Merriam-Webster (2018)

Origins of Stigma: How Prevention/Education/Intervention Messages Unwittingly Reinforce Stigma

- Creates more stress for the already stressed mother (1 binge can harm your child).
- Focus on individual choice versus social context (FASD 100% preventable).
- Zero compassion for the recipients of the prevention/education message (Stigma is immediate once the mother knows she is pregnant).
- Confirms the bad mother story (focus on problems versus worth of the mother and child, compared to other childhood diagnosis).

Choate, P.W. (2017)

Stigma: Unconscious Bias

- Leads to streams of thoughts and attitudes that follow misperceptions about an individual.
- Stirs up triggers in our own interpersonal lives.
- Continues an inertia of rigidity in policy making.
- The diagnosis of FASD has an overwhelming response from educators and mental health clinicians, who may not feel competent, which in itself creates a stigma of poor prognosis and hopelessness.
- Perpetuates the myth that these children cannot learn.

McIntee, C. L. (2018)

Compounded Systematic Stigma

- Intergenerational trauma.
- Poverty.
- Addiction.
- Mental health.
- Childhood abuse, rape, violence.
- Social isolation due to recovery and sobriety.
- Immediate involvement in Child Welfare system.
- Disproportionate representation of Aboriginal Nations.

Choate, P.W (2017)

FASD Stigma and Unique Barriers for Parents/Caregivers:

Birth Mothers

- Stigma towards the self in forms of guilt, shame, judgment, and loss of voice.
- Not seen in context of possible isolation, intergenerational trauma/addiction, undiagnosed learning disabilities or FASD, fear of losing child (MCFD), little resources, single parent, judgment, complex grief, homelessness.
- Stigma regarding cultural, economic, and professional backgrounds of birth mothers. (She should have known better).

McIntee, C. L. (2018)

Adoptive Parents and Relative Caregivers

- Unsuspected diagnosis, childhood trauma (Parent may not have information), burnout, parental blame, family isolation, little resources, adoption breakdown, marital breakdown, complex grief.
- Reactive Attachment Disorder (RAD).
- Managing the stigma you feel as an adoptive parent, or as a relative caregiver.

McIntee, C. L. (2018)

Foster Parent

- MCFD expectations, short/long term placement expectations, cultural expectations, family reunification transitions, stereotyping the ethics of the foster caregiver, feeling caught in the middle between systems, and family reunification.
- Balancing professional with parental role.

McIntee, C. L. (2018)

What all Caregivers Have in Common:
STIGMA

- Compounded Stigma.
- Life long Complex systems to navigate.
- Little resources and no respite without taking sever steps.
- Blamed for behavior.
- Seen in hopeless light and messages do not focus on context or strengths.

Living with the Diagnosis of FASD
and Compounded Stigma

- Stigma and correlation to primary/secondary symptom exacerbation.
- Increase risk of self-rejection.
- Strengths are undervalued while unrealistic expectations increase.
- Misinterpretation of behavior as manipulation, versus trying to meet needs.
- Feeling like no one can help them, they are a throw away person.

McIntee, C. L. (2018)

Stigma and Complex Grief

- Birth: Life long issue of feeling failure/responsible, the journey towards recovery and self-forgiveness, telling your child, family, friends, and colleagues.
- Relative: Grandparents who have already raised a family, and may have an adult child still not in recovery. Aunts/Uncles raising families and supporting an adult sibling's child, who also may not be in recovery.
- Adoptive: Adoptive breakdown and loss, difficulty bonding, child pinning to know about their birth family, grief and loss of letting go no matter how much love you give.
- Foster: FASD and spectrum differences for each child placed in your care. Learning curve of how much love is too much to give.

McIntee, C. L. (2018)

Educational Systems: Broken Promises

- The actual reality after diagnosis and no SEA support.
- Confidentiality and your right to disclose or not to disclose.
- When a child comes to school dysregulated it is seen as something wrong with parents versus part of the spectrum itself.
- Easier to blame then to create solutions based on strengths.
- Educator rigidity based on stigma attitudes towards the child and caregivers: This is a parenting problem.
- Sometimes children have to change learning environments to fit their needs.

McIntee, C. L. (2018)

Child Mental Health: "Well it is FASD."

- Underfunded child mental health system with little appropriate support for children with FASD.
- A call to 911, child is taken to hospital, after sever aggressive, violent, suicidal, outbursts, and sent back home after calmed down in the middle of the night.
- When admitted different medical practitioners every day, and every meeting.
- Sever unrealistic expectations of parents/caregivers to provide 24/7 care during suicide watch.
- FASD education is not enough to support families.

McIntee, C. L. (2018)

What Parents/Caregivers Say Helps: Moving Through Compounded Stigma

- Feeling understood/emotional support.
- Learning the right words to say to family/professionals.
- Connecting to community.
- Help with navigating systems.
- Knowing you are not alone.
- Self-care which includes humor.
- Creating success based on unique family strengths.
- Moving through grief caused by stigma to become a advocator for yourself, and your child/children.

McIntee, C. L. (2018)

Increase Well Being By Acknowledging Strengths and Successes

- Working from the heart to brain/body perspective.
- Assess marital discord & parenting isolation.
- What has been working and do more of that.
- Working from a team approach with parents/caregivers.
- Build multidisciplinary teams based on compassion.
- Take self-care seriously for both the client and yourself.
- Advocate and challenge systems regarding the complex grief and compounded stigma.

Salem, M.O. (2004), McIntee, C. L. (2018)

Prevention Without Stigma

- 1. Fetal alcohol spectrum disorders (FASD) is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy.
- NOFAS FINAL : Fetal alcohol spectrum disorders (FASD) is an umbrella term describing the range of effects that can occur in an individual who was exposed to alcohol before birth.

Tavenner Mitchell, K. (2016)

2. FASDs are caused by a woman drinking alcohol during pregnancy.

- NOFAS FINAL : FASDs can occur in an individual who was exposed to alcohol before birth.

8. When a pregnant woman drinks alcohol, so does her baby.

- NOFAS FINAL : A developing baby is exposed to the same concentration of alcohol as the mother during pregnancy.

9. To prevent FASDs, a woman should not drink alcohol while she is pregnant, or if she might be pregnant.

- NOFAS FINAL : Make a plan for a healthy baby – don't drink any alcohol if you are pregnant or could become pregnant.

Tavenner Mitchell, K. (2016)



We need to change their minds!
(Eleven year old child with FASD)

freedigitalphotos.net

Give a Hand Up



Istockphoto.com

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