



Date: Tuesday, March 5, 2024 9:00 am – 11:00 am

Meeting Minutes

1. In Attendance & Welcome: Lisa, Brittany, Carol, Denise, Lynne, John, Beth, Bernie, Deepa, Roxanna, Sophia, Leona, Nola, Miranda, Raelee, Mariam, Sadie, Sarah, Barb

2. Action Follow Up – February

- **Action:** Lisa will create an online event registration form.
 - Completed, posted March 1, 2024 on EFAN blog.
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3. Reporting

- Quarter 4: January 1, 2024 – March 31, 2024
 - ORS due no later than 9am on Friday, April 5, 2024.
 - Narrative report due no later than Friday, April 12, 2024.
 - Unaudited Schedule Bs are due April 30, 2024
 - Audited Schedule Bs are due June 30, 2024
 - EFAN Annual Report is due to the GoA on April 30, 2024.
 - Please ensure Letters of Agreement are returned.
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4. Finances

- No expenditures to note.
 - Upcoming: Survey Monkey, room rental (May, June, August, September, October).
 - New banner for EFAN
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5. Health Outcomes Fund Applications

- Bissell: FASS
 - Motion (Lisa), to approve the FASS request in the amount of \$2,600, seconded (Brittany), carried.
 - Please email Lisa the data that needs to be included in ORS.
 - Please email Lisa if the activity schedule is done and there is no data to include.
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6. FASD Frontline Collective

- FASD Frontline Collective: Spring Fling
 - Tuesday, April 23, 2024, 9:00 am – 11:00 am.
 - Location: Unlimited Potential, 10403 172 Street, Unit 145.
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Meeting Minutes

- Agenda includes meet and greet and deep dive into what are we doing well and where can we improve in relation to the 'Towards Healthy Outcomes Model version 2' (small group).
- Will email the THO version 2 to all registrants prior to event within questions to consider.
- Register at: <https://edmontonfetalalcoholnetwork.org/2024/03/04/fasd-frontline-collective-spring-fling/>

7. In Focus: Persons with Developmental Disabilities (PDD)

- Not black and white, grey areas.
- Trying to avoid mentorship programming being provided to individuals who are receiving PDD supports.
- FASD frontline mentorship programs were created to support individuals who did not qualify or could not access PDD services for various reasons.
- Programs should not look for reasons to not support an individual with FASD, but rather we want to ensure we can support as many individuals as possible through the FASD Networks and PDD.
- Transition planning should include PDD and AISH applications.
- Programs can determine their own processes for soft-transfers.
- If transferring services to a PDD funded program please provide EFAN contact information and details around foundations of FASD training and professional development that can be provided to the PDD programs.

8. 'Prevention Conversation' Project – Brittany

- Two day in-person strategic planning session planned for May.

9. 'WRaP 2.0 FASD Coaching Partnership' Project

- Year 4 has begun.
- Asking the Networks and coaches to look at their year 3 reports and use the data results to inform their year 4 work and determine if the data speaks accurately to what is being accomplished.
- Expecting a meeting invite with the GoA to discuss what it is they need to plan for the end of the WRaP 2.0 current version, plans for after year 5?

- New Research & Resources

- '*FASD Beyond the Spectrum*' - Evening (registration, panel discussion, networking event) and a full-day. - Tuesday Oct 22, Wednesday Oct 23rd will be full day
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Meeting Minutes

- Lisa is going to put a 'sponsorship' post up on the EFAN blog.
 - Emailed the staff responsible for the booths (\$300/per) and mentioned EFAN, Prevention Conversation and WRaP would like a booth.
 - 22nd: 5:00 – 9:00 pm, registration, key note (Dr. DaSilva), panel discussion, mocktails & Networking
 - 23rd: 8:00 am – 5:00 pm
 - *'No one believed us: no one came to help': caregivers' experiences of violence and abuse involving children with fetal alcohol spectrum disorder: Anita Gibbs*
 - <https://edmontonfetalalcoholnetwork.org/2024/02/21/no-one-believed-us-no-one-came-to-help-caregivers-experiences-of-violence-and-abuse-involving-children-with-fetal-alcohol-spectrum-disorder/>
 - Examined child and adolescent-to-parent violence and abuse, CAPVA, to caregivers of children with FASD.
 - CAPVA refers to abusive and violent behaviours by children towards their parents or primary caregivers.
 - The abuse and harmful behaviours can include a full range of physical, emotional, verbal, financial, and material actions over prolonged periods of time.
 - Theme 1 (experiences and types): For 32 out of 56 participants, CAPVA was present (57%). A range of physical, verbal, property, emotional, and financial abuse was noted. Self-harm and violence to animals were also noted
 - Theme 2 (impacts): The impacts of CAPVA on parents and caregivers were wide ranging and impacted how they viewed their health and mental well-being; how they viewed their relationships; and how their finances were impacted.
 - Theme 3 (systemic abuse): While caregivers understood that much of the abuse and harm they faced was coming from children with unmet communication, education, and sensory needs they felt the professionals they spoke to did not share their views. Many of the caregivers interviewed expressed deep dismay and disappointment at caring professionals who made them feel that they were to blame for the abuse and that the problem of abuse was not 'that serious.'
 - Theme 4 (strategies): Parent interviewees were innovative and skilled at implementing a range of strategies aimed at de-escalation, distraction, and restoring relationships once an incident was over. Caregivers had safety plans, used humour during tense moments and tried to cope with their child's dysregulation with calm soothing communication strategies.
 - Theme 5 (silverlinings): While the struggles with CAPVA were insurmountable, at times caregivers were able to note some positives about the impact of parenting a child with FASD and the lives they had been living. Caregivers talked often of 'personal growth,'
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Meeting Minutes

developing 'more empathy,' and using their experiences to 'help others' facing similar challenges.

Key points

- Violence and abuse from children and adolescents are significant and frequent issues for caregivers of children who have fetal alcohol spectrum disorder. The abuse and violence impact caregivers' relationships, health, and finances.
- Caregivers are resilient and have developed a range of strategies to de-escalate and survive the violence and abuse from their children.
- Caregivers note the lack of understanding from caring professionals and want to see changes where the violence and abuse are acknowledged, where training is provided, and where FASD services are funded.
- Practitioners can demonstrate empathy and support in many forms notably in demonstrating belief and by making efforts to secure more-than-superficial help for families.

10. Round Table – Discussion

11. Upcoming Meetings: April 2, 2024 (Catholic Social Services office 11405 – 163 Street)
