

# ETHICAL CONSIDERATIONS WHEN COMMUNICATING A DIAGNOSIS OF A FETAL ALCOHOL SPECTRUM DISORDER TO A CHILD

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## ABSTRACT

Maternal alcohol consumption during pregnancy may result in Fetal Alcohol Spectrum Disorder (FASD), which is an umbrella term used to describe a range of conditions that are associated with significant neurodevelopmental impairments. Communicating an FASD diagnosis to a child is a complex and difficult task that requires a great deal of care, particularly due to the sensitive nature of the etiology of these disorders. To the best of our knowledge, there are no formal guidelines or published materials that outline the ethical considerations specifically associated with disclosing an FASD diagnosis to a child. This paper discusses a number of ethical principles and situational factors that should be considered when communicating an FASD diagnosis, as well as some of the potential risks and benefits associated with disclosure. We also provide recommendations to assist clinicians in communicating the diagnosis in a manner that increases understanding and minimizes harm to the child. Future recommendations include the development of formalized guidelines in order to aid clinicians in carrying out this sensitive task.

**Key Words:** *FASD, diagnosis, disclosure, children, ethics*

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Approximately 1 in 100 individuals in North America are affected by Fetal Alcohol Spectrum Disorder (FASD).<sup>1</sup> FASD is a non-diagnostic term used to describe a range of adverse physical, cognitive, and behavioural outcomes that may result from exposure to alcohol in utero. According to Canadian diagnostic guidelines, four specific diagnoses are included under the spectrum of FASD: Fetal Alcohol Syndrome (FAS), Partial Fetal Alcohol Syndrome (pFAS), Alcohol-Related Neurodevelopmental Disorder (ARND), and Alcohol-Related Birth Defect (ARBD).<sup>2</sup>

Although an FASD is currently considered a medical diagnosis, a thorough neuropsychological and psychoeducational assessment is central to the diagnostic process, thus necessitating a multidisciplinary diagnostic team led by both a physician and clinical psychologist or neuropsychologist. Given that neuropsychological impairments are the most common result of prenatal alcohol exposure<sup>1</sup> and are core features of

alcohol-related disorders, the psychologist often plays a central role in communicating the actual FASD diagnosis to caregivers and to the child. Clinicians, however, have no specific ethical guidelines available to aid them in this difficult task. Moreover, to our knowledge, there are no published materials that discuss ethical considerations related to conducting FASD diagnostic assessments with children. In our clinical and research experience working with this vulnerable population, we have identified a number of ethical principles and standards that should be considered and balanced when conducting an FASD assessment and disclosing an FASD diagnosis to a child. These include ethical principles and standards related to psychological testing and assessment, the rights of test takers, clarity and honesty in communication, and respect for the dignity of individuals.

The scope of this paper will be limited to the discussion of ethical considerations related to assessing and diagnosing children and youth with

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FASD who are deemed incapable of consenting for their own treatment (i.e., diagnostic assessment). In general, children with FASD may be more likely than typically developing children to be deemed incapable of providing informed consent because they present with a wide range of neurodevelopmental impairments, which may include lower intellectual functioning, memory impairments, difficulties comprehending abstract concepts, and severe executive dysfunction (for a review see<sup>3-5</sup>). These impairments may limit the child's capacity to understand information relevant to the decision to consent to the assessment and appreciate the consequences of giving, not giving, or withdrawing consent.<sup>6</sup> However, as always, the capacity to consent must be determined on a case-by-case basis before the commencement of the diagnostic assessment.

#### **Considerations for Obtaining Informed Consent**

Before conducting an FASD assessment with a child deemed incapable of providing informed consent, it is necessary to obtain informed consent from the child's legal guardian, who in such a case would be deemed a substitute decision maker.<sup>7</sup> Children referred for an FASD assessment typically have a range of legal guardians including biological parents, adoptive parents, grandparents, older siblings, aunts/uncles, and Children's Aid Societies or Child Welfare Agencies. Clinical teams conducting diagnostic assessments of children with suspected FASD must be aware of this range of potential legal guardians, and must be prepared to take extra steps in order to accurately determine the person who is lawfully entitled to act as a substitute decision maker for the purpose of giving consent for the assessment. The clinician responsible for conducting the FASD assessment should always confirm the child's legal guardian in order to ensure that informed consent is obtained from the appropriate person, which is not always clear at the time of referral. One should be aware that the referral source and the person legally responsible for consent are not necessarily one in the same. For example, a foster parent may request the assessment and accompany the child to the testing; however, the assessment cannot be conducted unless consent is obtained from the legal guardian. This could be the biological parent or another relative in cases of voluntary interim

placements, or could be the child's social worker and Children's Aid Society or Child Welfare Agency in cases of crown wardship.

Standard 8.4 in the Standards for Educational and Psychological Testing, developed jointly by the American Psychological Association, American Educational Research Association and National Council on Measurement in Education, explicitly recommends that informed consent should be obtained from test takers or their legal guardians, in which they are made aware of the procedures, processes, and potential risks and benefits associated with the assessment.<sup>8</sup> Thus, in cases when the child presents with suspected prenatal alcohol exposure, the legal guardian should be made fully aware that the testing may result in an FASD diagnosis before the assessment commences. Standard 8.4 in the Standards for Educational and Psychological Testing also states that younger children should be given an explanation as to why they are undergoing an assessment using language they can understand;<sup>8</sup> however, how to do this and exactly what needs to be said is left up to the discretion of the individual clinician. The clinician should weigh the risks and benefits of telling the child that the assessment is an inquiry into FASD, as early as feasible in the assessment process. When making this decision, the clinician should consider the following ethical principles articulated in the Canadian Psychological Association's Canadian Code of Ethics for Psychologists: (1) seeking willing and adequate informed participation from any persons of diminished capacity to give informed consent (Principle I.35); (2) avoiding doing harm to the child (Principle II.1); and (3) the values of straightforwardness and openness (Principle III – Integrity in Relationships).<sup>9</sup> Being fully transparent regarding the purpose of the assessment would necessitate implying to the child that his/her mother consumed alcohol during pregnancy, and that this may have caused him/her harm. Although one needs to make a reasonable effort to garner informed participation from the child, one must also ensure that more harm than good does not come to the child in the process. The very nature of explaining the purpose of the assessment has the potential to disclose information that may negatively impact the child's relationship with his/her mother, emotional well-being, and self-concept (these potential harms will

be described in detail below). Suggesting, at the outset of the assessment, that the child's mother may have done something during pregnancy that has caused damage to the child's brain may be particularly unnecessary and harmful considering receipt of an FASD diagnosis is not guaranteed. If the child does not meet the criteria for an FASD, then sufficient evidence does not exist to support the notion that the mother's alcohol consumption during pregnancy caused significant harm to the child's development. However, if one has already fully explained the purpose of the testing to the child, then one may have caused irremediable harm by implying that the mother's drinking during pregnancy could have damaged the child's brain. Disclosing this sensitive piece of information may cause children to question their relationships with their mothers and their mothers' risky behaviours during pregnancy. Furthermore, by explaining that the assessment is an inquiry into FASD, the clinician is also implying to the child that his/her mother consumed alcohol during pregnancy. However, this may not be the case, as diagnostic assessments are conducted even if there's a lack of documented in-utero alcohol exposure, as a diagnosis of Fetal Alcohol Syndrome does not require confirmation of exposure.<sup>2</sup> Thus, at the outset of the assessment, it is recommended that clinicians explain the reasons for the testing without specifically implicating the mother's actions during pregnancy as a potential cause of the child's presenting difficulties. We believe the best way to avoid harm at this stage, while remaining as open and honest as possible, would be to explain that the purpose of the assessment is to find out more about how the child thinks and learns, identify what areas the child may have more difficulties in, and determine whether these difficulties were caused by something that may have happened to the child during pregnancy.

### **Consideration of Risks and Benefits of Communicating the Diagnosis**

Once the diagnostic assessment is complete and it has been determined that the child meets the criteria for an FASD diagnosis, there are a number of situational factors and ethical principals the must be considered before deciding when and how to sensitively disclose the diagnosis to the child. Situational factors include the child's age

and developmental level, the child's specific profile of impairments, the child's current mental health, the stability of the child's current living situation, and the legal guardian's concerns related to disclosure. Furthermore, the following ethical principles from the Canadian Code of Ethics for Psychologists must be considered and balanced: protecting and promoting the welfare of the child (Principle II.1), avoiding doing harm to the child (Principle II.2), not carrying out an activity unless probable benefits are proportionally greater than potential harms (Principle II.17), trying to communicate completely and objectively knowledge, findings, and views (Principle III.11), providing appropriate information regarding the results of the assessment to all persons involved (if appropriate) (Principle III.15), and upholding the expectation of honesty, openness, and straightforwardness (Principle III – Integrity in Relationships).<sup>9</sup>

Furthermore, when communicating the diagnosis to the child, the clinician should consider Standard 14.6 from the College of Psychologists of Ontario Standards of Professional Conduct, which relates to clarity of communication and presenting information in a manner that can be understood by the child.<sup>10</sup> Overall, the goal is to communicate the assessment results to the child, in an honest, straightforward, and open manner; however, this must be done with respect and dignity for the child and in the context of responsible caring.<sup>9</sup> Above all, the clinician must promote the welfare of the child and avoid causing harm. The term "harm" also applies to the child's psychological well-being, and includes harm to family relationships, personal identity, self-worth, and interpersonal trust.<sup>9</sup> Thus, the clinician must: (1) determine the potential harms and benefits of disclosing the FASD diagnosis to the child; (2) communicate the diagnosis in a manner that reduces the likelihood of harm and maximizes the potential benefits; and (3) only proceed with disclosure if the potential benefits outweigh the potential harms. It is also important to remember that the clinician has the greatest responsibility to the person in the most vulnerable position,<sup>9</sup> and in the context of an FASD diagnostic assessment, this is most often the child.

Unlike many other mental health disorders commonly diagnosed in childhood (e.g.,

Attention-Deficit/Hyperactivity Disorder, Autism Spectrum Disorder), a diagnosis of FASD is associated with a specific etiology. Communicating an FASD diagnosis to a child may result in psychological harm, as one is ultimately identifying the mother's choices and behaviours during pregnancy as the cause of the child's current impairments. Thus, when communicating a diagnosis, the clinician must strive to remain open and transparent, while simultaneously minimizing any harm to the child's psychological well-being and the mother-child relationship. Protecting the mother-child relationship is of particular importance when the child is still in the custody and care of his/her biological mother. By communicating an FASD diagnosis to a child, the clinician is conveying to the child that his/her brain damage and associated difficulties are the result of his/her mother's alcohol consumption during pregnancy. This harsh reality can lead to feelings of anger, sadness, and shame. The likelihood of causing harm increases drastically if the child comes to believe that his/her mother *purposely* caused damage to his/her brain by consuming alcohol while pregnant. The belief that one's mother intended to cause harm could lead to the formation of other cognitive distortions and negative cognitive schemas about the self and others (similar to when a child experiences abuse). For example, children may begin to view themselves as not worthy of being loved or protected, and develop an expectation that others will harm them, just like their mothers. The clinician is responsible for carefully evaluating the probability of causing harm to the child's psychological well-being, family relationships and personal identity by disclosing an FASD diagnosis, and must weigh these potential risks against the potential benefits of disclosure.

Communicating an FASD diagnosis to a child can also be associated with a variety of benefits, if disclosure is conducted in a sensitive manner. We postulated that in most cases, the potential benefits do outweigh the potential harms; however, a case-by-case risk-benefit analysis is always required. Putting a name to the difficulties that these children experience (e.g., FASD) can help to externalize their problems. Whereby, explanation of the diagnosis may demystify for the child his/her academic,

emotional, and behavioural difficulties, which could instil feelings of relief and a better understanding of oneself. When communicating the diagnosis, the clinician should always provide psychoeducation and highlight the prevalence of these disorders. Through an open and honest discussion about FASD, children learn that others have similar struggles. This step may help to normalize the child's experiences and reduce any feeling of isolation. Another possible long-term benefit of full disclosure is that the child may become sensitized to the negative effects of alcohol, which could positively affect his/her future choices regarding alcohol consumption.

Receiving an FASD diagnosis can be viewed as the first step in the "healing" process, as children are finally made aware of the origin of their challenges. By making the diagnosis, clinicians are now in the position to mitigate harm, as they can work closely with children to identify and challenge any negative or unhelpful beliefs they may have regarding their diagnosis and/or their relationship with their biological mothers. The principle of "Responsible Caring" articulated in the Canadian Code of Ethics states that psychologists are obligated to correct any harmful effects that have occurred as a direct result of their services.<sup>9</sup> However, if a clinician gives a child an FASD diagnosis, but fails to subsequently communicate that diagnosis to the child, then he/she cannot determine if any harm to the child has occurred as a result. Ultimately, one should assume responsibility for the child eventually discovering his/her diagnosis. Many of the potential psychological and relational harms associated with receiving an FASD diagnosis are somewhat inevitable (e.g., negative feelings towards biological mother), and thus delaying disclosure of the diagnosis will likely only postpone potential harm. Such a discovery later in life may lead to poorer outcomes if the necessary professional support is not in place. Moreover, feelings of betrayal and being deceived by their caregivers and clinicians may result from the diagnosis being concealed.

In our opinion, the only way clinicians can evaluate and mitigate any harm associated with giving a child an FASD label is if they communicate the diagnosis themselves. To that end, the diagnostic clinician should be the one who ultimately discloses the diagnosis to the

child, as he/she is best suited to provide a clear, accurate, sensitive and empathic explanation of the origin of the child's difficulties. Communicating an FASD diagnosis to a child is consistent with many general values and specific guidelines related to ethical Principle III: Integrity in Relationships, outlined in the Canadian Code of Ethics for Psychologists.<sup>9</sup> By practising full disclosure, the clinician is communicating his/her knowledge, the assessment results, and his/her interpretations completely, accurately, honestly, and in an open and straightforward manner.<sup>9</sup>

Concerns of causing harm to a child by fully disclosing an FASD diagnosis may lead some clinicians to choose to communicate the results of the neuropsychological assessment (e.g., strengths and weaknesses), without revealing the child's actual diagnostic label. However, omission of the organic nature and cause of their disability may result in additional harm. More specifically, children may come up with their own explanations for their impairments, which may be erroneous or even more harmful than the truth. The following clinical example, shared by a caregiver, helps to illustrate this point. One child with FASD, who was not made aware of her diagnosis, posed the question to her foster mother, "Am I just stupid?" The child's question stemmed from the realization that she had learning and behavioural differences compared to her peers in her regular classroom. This child also knew that some of her friends in her resource classroom were different because they had specific disabilities such as Asperger's Disorder, but this child did not understand what made her so different from her peers. Unfortunately, she was left to draw her own conclusions.

### **Minimizing Harm of the FASD Disclosure to the Child**

Once the clinician has determined that the potential benefits of disclosing an FASD diagnosis to a child outweigh the potential harms, the clinician must find a way to communicate the diagnosis in a manner that minimizes any reasonably foreseeable harm.<sup>9</sup> One way clinicians can do this is by explaining to children that their mothers did not mean to intentionally harm them while pregnant. Communicating this concept is important for two reasons: (1) in our clinical experience, this has almost always been the truth;

and (2) the opposite belief could be extremely detrimental to the child's emotional well-being and self-concept, as well as the mother-child relationship. Thus, the clinician must find a way to help the child understand how FASD could be caused inadvertently. If accurate, reasonable and developmentally appropriate, the clinician may want to emphasize some of the following concepts when communicating an FASD diagnosis to a child or youth:

1. Some mothers do not know they are pregnant until later in their pregnancies, and thus do not stop alcohol consumption in time.
2. Some mothers are not aware that alcohol can have harmful effects on the developing fetus, and thus do not realize that drinking during pregnancy can hurt their child.
3. Some mothers have serious mental health problems, including substance abuse/dependency issues, and thus may be less capable of controlling their alcohol consumption during their pregnancy.
4. Some mothers experience extremely difficult life circumstances during pregnancy (e.g., homelessness, domestic violence) and may use alcohol to help them cope with stress.
5. Some mothers come from families where their mothers consumed alcohol during pregnancy, and thus, they may believe that it is acceptable and harmless. These mothers may also suffer from FASD, which may contribute to poor decision making and planning in pregnancy.

Although the abovementioned concepts can be helpful when trying to explain how a child could be prenatally exposed to alcohol unintentionally and in developing an empathic understanding of the causes of FASD, the challenge comes with communicating these concepts in a developmentally appropriate manner, using age-appropriate language. For example, when explaining alcohol dependency to an older child, the clinician could say something such as: "Your mom was drinking for a long time before she got pregnant, and her body got very

used to the alcohol. When she tried to stop drinking, she would get very sick. So in a way, her body was telling her that she could not stop drinking all of a sudden, even though she was pregnant”.

When communicating an FASD diagnosis, clinicians should also try to identify and challenge any inaccurate or unhelpful beliefs the child may hold regarding the diagnosis (e.g., “having FASD means I’m stupid”, “my mom doesn’t love me because she drank during pregnancy”). We also recommend that clinicians avoid using the term “permanent brain damage” when describing the disorder, as this may lead children to erroneously believe that they will never be capable of improving their functioning. Conversely, it is often helpful to explain to children that they may have certain difficulties at home and/or at school because their brains developed differently when they were growing in their mothers’ tummies as babies. Clinicians may also want to explain to children that their brains work differently than other children’s brains, which is why some things may be more difficult for them. At this point, the clinician can begin discussing the child’s specific neurodevelopmental weaknesses; however, it is recommended to end the feedback session by highlighting the child’s strengths. It is critical to end the feedback on a positive note, and clinicians should do everything in their power to promote feelings of self-worth.

### **Maximizing Understanding When Communicating an FASD Diagnosis**

During the feedback session, the clinician must make a reasonable effort to present the assessment results and diagnosis in a manner that is likely to be understood by the child.<sup>10</sup> This ethical principle is particularly relevant when communicating a diagnosis to a child affected by FASD, as these disorders are associated with a number of neurodevelopmental impairments that often affect the child’s ability to understand and retain information. For example, many children with FASD have below average memory abilities<sup>11-14</sup> and tend to have specific difficulties with encoding verbal information.<sup>15</sup> Thus, children with FASD may fail to retain much of the verbal information presented in a feedback session. In addition to the child’s age and developmental level, we recommend clinicians consider the

child’s unique neurocognitive profile when preparing for a feedback session, and present information in a manner that facilitates encoding and retention. More specifically, it is recommended that clinicians use concrete and developmentally appropriate terminology, repeat key points during the feedback session, and provide the child with a written hand-out, which contains information that is critical for the child to understand and retain. Encoding and retention can also be facilitated by the use of visual aids, such as picture books and diagrams. *Forgetful Frankie* is one picture book that can be used to help explain the diagnosis to younger children.<sup>16</sup> Clinicians can also create their own picture books aimed at children of different ages, in order to help facilitate sensitive understanding of the topic.

### **Postponing Disclosure of the Diagnosis**

Although developmentally appropriate communication of an FASD diagnosis is recommended in most cases, there are a number of specific circumstances which may necessitate postponing full disclosure of a diagnosis to a child. Very young children often do not have the cognitive and developmental capacity to fully understand and appreciate their FASD diagnosis. In these cases, the FASD diagnosis could be explained as a “boo-boo” in the child’s brain that happened when the child was a small baby in his/her mother’s tummy. The communication of an FASD diagnosis may also be contraindicated in cases when the child is presenting with self-harm or suicidal behaviour. In these cases, the negative feelings and beliefs that could be brought on by the disclosure are more likely to lead to serious harm. Thus, when self-harm or suicidal behaviour is present, the potential immediate harms of disclosure may outweigh the potential benefits. Clearly, this is not an exhaustive list of possible circumstances where postponing disclosure would be ethically indicated. Thus, the clinician must always strive to identify any potential harms associated with communicating a diagnosis to a child, and must only proceed when the potential benefits are proportionally greater than the potential harms.<sup>9</sup>

In cases where the diagnosis is not communicated to the child at the time of the assessment, it is strongly recommended that the diagnosing clinician follow-up with the family

and provide a more comprehensive explanation of FASD to the child at a later date. Often, if the clinician does not communicate the diagnosis at the time of the assessment, the responsibility is ultimately passed on to the parent/caregiver. However, many parents/caregivers may not be capable of providing a sensitive and developmentally appropriate explanation of the disorder, nor should they be expected to. It is our belief that the clinician conducting the FASD assessment is ethically responsible for communicating the diagnosis to the child, regardless of the time lapse between the actual diagnostic testing and when the child is developmentally capable of understanding an explanation of the disorder and/or emotionally and physically stable enough for disclosure. It is also our belief that children ultimately need to be made aware of their FASD diagnosis, as in time, many will inevitably be responsible for their own care, and will have to become self-advocates and seek out appropriate services. This is of particular importance considering many children with FASD are in the custody and care of a Children's Aid Society or Child Welfare Agency, and are often left to fend for themselves upon reaching 18 years of age.

Finally, clinicians may run into the case where a legal guardian does not want the child to be made aware of the FASD diagnosis. The guardian may even refuse to bring the child back to the clinic for a feedback session. A guardian may be wary of disclosure of the diagnosis to the child for a variety of reasons. For example, they may believe that disclosure of the diagnosis would cause irreparable damage to the child's self-esteem and/or the mother-child relationship. They may not want the child to feel that he/she is different than or inferior to other children. Alternatively, they may fear that the child will become defeated by the diagnosis and use it in the future as an "excuse" for poor performance. The clinician should do his/her best to address the guardian's concerns; however, it is the clinician's responsibility to act in the best interest of the most vulnerable person, which in most cases, would be the child.<sup>9</sup> The clinician should respect the legal guardian's concerns and take reasonable measures not to undermine the guardian's ability to make decisions for the child.<sup>9</sup> However, if the clinician truly believes that the probable benefits of

communicating the FASD diagnosis vastly outweigh the potential harms, then he/she must make a reasonable effort to explain this to the guardian. If, after clearly discussing all the potential advantages and harms associated with disclosure, the legal guardian still does not consent to the clinician communicating the diagnosis to his/her child, then the clinician has to ultimately respect the guardian's wishes.

## SUMMARY AND CONCLUSION

In summary, there are a variety of ethical considerations involved in conducting an FASD diagnostic assessment with a child who is incapable of giving informed consent. Psychologists and physicians who are familiar with these ethical issues need to collaborate and develop clear ethical guidelines specifically related to communicating FASD diagnoses to children. Until these guidelines are made available, it is recommended that clinicians consult with colleagues when faced with ethical issues related to this topic. Overall, clinicians should try to identify the potential benefits and harms related to full disclosure of an FASD diagnosis to a child on a case-by-case basis, and only proceed if the benefits outweigh the harms. If disclosing the diagnosis is deemed beneficial, then the clinician needs to make every possible effort to minimize associated harms, and communicate the diagnosis in a sensitive manner that can be understood and retained by the child. Ultimately, children will need to be made aware of their FASD diagnosis at some point in their lives. Communication of an FASD diagnosis requires many ethical considerations given the sensitive nature of the origin of the disorder and implications that such an origin may have on the child's self-worth and mother-child relationship. Formalized ethical guidelines are necessary in order to aid clinicians in carrying out this challenging task.

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