The Prevention and Management of Fetal Alcohol Spectrum Disorder(s)(FASDs) in Ireland: A Public Policy Gap?

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Introduction

Ireland continues to be at high risk for alcohol-related harm and is repeatedly flagged in both national and international commentary on the culture's harmful drinking patterns and high levels of episodic drinking for both genders. Within the EU, Ireland has one of the highest per capita alcohol consumption rates, with alcohol consumption levels forecast to increase over the next decade (Manthey et al., 2019). As we enter the year 2024, we also move into the 56th year of alcohol in pregnancy research, and the subsequent birth of children suffering the destructive effects of alcohol on Fetal development. (Dyląg et al., 2023; Lemione et al., 1968). Culturally, in Ireland, various domestic researchers have provided a wealth of evidence-based guidance to Irish state officials to address this insidious public health issue (Barry et al., 2007, Catterick & Curran, 2014; L. Curran, 2007; W. C. Curran & Danbrook, (2023a, 2023b); W. L. Curran, 2020; Mullally et al., 2011; O'Keeffe et al., 2015). What has been clearly articulated over the decades of fetal alcohol research is the clear need of culturally sensitive and appropriate policy and procedure to address this difficult, but urgent, public health need. Furthermore, what is of equally pressing nature to address this public health need through public policy is an escalating and ballooning cost burden, which recently topped 10 billion a year according to Jonsson (2019) in his paper a 'Policy Perspective', which advocates for an increased policy focus on Fetal Alcohol Spectrum Disorder (FASD). FASD is a complex and progressive disability, which affects millions of individuals around the world. In a recent publication Burd & Popova (2019) offered that there is now an estimated 11.2 million individuals under the age of 18 in the world impacted at some level from prenatal alcohol exposure. Coupled with this pressing policy need to alleviate public costs, is the substantial evidence of the considerable impact FASD places on individuals, caregivers, and state systems of care, with Tusla experiencing increased demands from individuals with, or suspected of having, FASD, and their caregivers.

Background

Each year in Ireland and in countries all over the world, children are born with varying degrees of brain injury resulting from prenatal alcohol exposure (PAE) (Jonsson, 2019; Warren, 2015).

Such evidence underscores the need for universal prevention initiatives targeting maternal alcohol consumption, screening protocols, and improved access to assessment services, especially in special populations such as child welfare service structures. Although the science of alcohol risks to the developing fetus is plentiful, such scientific evidence has suffered significantly in overcoming the barriers on knowledge translation. Unfortunately, this has resulted in significant contradictions and confusion on the frontlines of public health prevention activities. Although the Lancet Journal warned of collateral damage from increased births of FASD post-pandemic (Sher, 2020), unfortunately, this again has fallen on deaf ears in our public policy. In truth, we have reached a point in 2024 where sweeping FASD under the *proverbial rug* is no longer a viable option. We need robust, pragmatic, and workable policy initiatives across all service structures of state and voluntary providers.

For decades, alcohol has been shown and highlighted as a teratogen—a poison that interferes with the development of the Fetal brain, face, and organs (Patel et al., 2019; Riley & McGee, 2005). Alcohol readily crosses the placenta, travelling into the fetus bloodstream, where it is shown to interfere with the developing embryo and fetus. Alcohol use in pregnancy can cause miscarriage and premature birth and can result in low-birth-weight babies. However, one of its most dangerous attributes is that it can alter the sensitive construction of the Fetal brain, changing the prescribed wiring structures of normal brain development. As the child grows and develops this impaired wiring impacts their ability to conform to normal developmental stages. It can often result in the child not being able to be raised in birth family, instead entering state systems of care.

Jones and Smith (1973) described Fetal alcohol syndrome among eight children from the Washington child welfare system born to alcoholic mothers 51 years ago. Here we see the first direct link of Fetal alcohol to child welfare services, presented as it was under the ‘failure to thrive’. Typically, these eight children were small and grew and developed poorly, leading to their having a’ failure to thrive’ label from the child welfare assessment process. They had a characteristic face that included narrow eye openings, a thin upper lip, and an indistinct philtrum—the area between the base of the nose and the upper lip. Due to advancements in medical science, we now know that the children described in the Jones and Smith paper are just one group of several alcohol-related injuries suffered by the fetus due to alcohol intake during pregnancy.

In 2004, the Centers for Disease Control (CDC) introduced the term Fetal alcohol spectrum disorder (FASD) to describe a constellation of effects suffered by the fetus when exposed to alcohol in the womb. What we know now is that a large percentage of these children born of an alcohol-exposed pregnancy (AEP) will not suffer from physical or facial abnormalities. As of May 2013, the New DSM-V introduced the term neurodevelopment disorder due to prenatal alcohol exposure (ND-PAE). This condition is concealed or hidden within the brain but provides a strong causal effect on the individual’s ability to conform to the norms of societal regulation and expectations in line with their chronological age.

As previously noted in this paper, the relationship of Fetal alcohol to our child welfare services has been shown since the Jones and Smith article (Jones & Smith, 1973), which documented the lives of eight children suffering 'failure to thrive" in the Washington State child welfare service. Since 1973, a large body of empirical evidence has developed to substantiate the connection of FASD to child welfare work (Chasnoff et al., 2015; Popova et al., 2014; Jirikowic et al., 2010; Fuchs et al., 2008). Currently, many of these children do not receive the required interventions and supports their disability requires due to poor professional education on FASD and a lack of screening tools and protocol. Without intervention or recognition, such children have a significant probability of developing secondary disabilities such as lifelong mental health illnesses, addiction difficulties, homelessness, trouble with the law, and school failure.

The Gaps in FASD Management

Although we are drowning in evidence-based solutions offered in peer-reviewed research, we have a major weakness in understating the pragmatic response needed to this public health issue. Primarily, from the outset, cultures that address PAE and FASD need to acknowledge four different, but integrated, strategy objectives in a culturally and linguistically diverse approach to policy and procedure development. These are:

1. Prevention of alcohol-exposed pregnancies
2. Identification and assessment of Fetal and alcohol-related harm in children and adults
3. Service delivery
4. The legal, ethical, and moral underpinnings of steps 1–3

Prevention

Prevention of alcohol exposed pregnancies within Ireland has received dismal attention for public health over the years. Although indigenous researchers have done the groundwork and produced critical evidence to inform public health strategies, prevention still receives very little attention. Epidemiologists addressing the prevalence of alcohol use in pregnancy have shown exceedingly high rates, such as the longitudinal study by Barry and colleagues offering a 65% alcohol in pregnancy rate (Barry et al., 2007). This study has been followed by single studies by Mullally and colleagues finding an 82% rate (Mullally et al., 2011) and O'Keeffe and colleagues bring in a similar 80% rate in 2015 (O'Keeffe et al., 2015). Together these three studies offer a heightened awareness that fetal harm from an alcohol exposed pregnancy is at high levels within Irish culture. It goes without saying that the prevention of fetal alcohol harm offers tremendous benefits of both social and monetary value to society. Although Ireland is making tentative steps in it prevention strategies, there is still a great need for such strategies to be universal and continuous in application.

Having a single approach of placing prevention literature on state web pages cannot be considered as a universal step. Prevention materials need to be multifaceted, written in plain

English and easily accessible physically in a range of locations where state services. An additional strategy may be that as described by Curran (2020), where he discussed integrating prevention messages into Social, Personal and Health Education (SPHE) in second-level education settings. This recommendation acknowledges that Ireland has a significant challenge on reducing, and educating on, fetal alcohol harm. Providing prevention materials within the SPHE programs of second-level education helps to minimize the risk of stigma. Whatever approaches adopted within prevention strategies, such approaches need to be driven through a lens of maternal-child health, ensuring that state providers don't instigate and promote stigma against women of childbearing age (Drabble et al., 2011). Prevention needs to be about empowering women of childbearing age with the correct information. What is shown in research is that cultural insensitivity to both the prevention of alcohol-exposed pregnancies and the psychosocial interventions for children living with an FASD contains high-risks of imparting stigma, which isolates both women and children from professional help and supports. Clearly, an alternative to punitive, insensitive approaches is that education, drug and alcohol services with a maternal focus are strategically positioned to prevent the harm associated with prenatal alcohol exposure. Studies have shown that pregnant women who abuse alcohol want to know, and want clear informed information that is rooted in scientific rigor, as women want to protect their fetus and are open to change (Holland et al., 2015; Murphy & Rosenbaum, 1999).

Identification/Assessment

A major impediment to meeting the needs of those living with the impact of an alcohol exposed pregnancy (AEP) is the large percentage of those living with no physical attributes. Research has shown that up to 85-90% of children living with harm from an AEP, will have no outward physical signs, unlike the smaller percentage living with Fetal Alcohol Syndrome (FAS) of around 10-15% (Jonsson, 2019). Society is aware and educated to this vulnerable cohort due to their dysmorphic features. Unfortunately, as noted, those most in need within the FASD discourse, are children whose neuro-disability is not in the face but concealed within the central nervous system (CNS), and who are poorly identified. Identification therefore of this brain impairment is complex and tedious. This is why Curran and Danbrook (2023) brought forward the social lens model to 'Capture Invisibility', which offers a non-labelling neurodevelopmental screening to disentangle the hidden nature of FASD, while at the same time identifying other more common neurodisabilities that can present with a similar profile to FASD.

Diagnostic Services

Although, as discussed, even though we are over a half-a century advanced in researching and understanding fetal alcohol harm, we still have major confusion and contradictions surrounding the diagnosing of FASD. What is receiving debate in the early diagnostic mantra, is that the many and varied presentations of FASDs, make it extremely difficult to identify, screen and diagnose a FASD (Brown et al., 2017). After a half century of research on the outcomes of prenatal alcohol exposure, there is still a lack of consensus on 'diagnostic categories and conditions' (Bastons- Compta, Astals, and Garcia-Algar, 2016). With the confusion on diagnostics, child welfare service and social workers are left without direction on the statutory duties of keeping children safe and understanding what services are needed. Domeij et al., (2018) showed that a diagnosis of FASD may increase stigma and isolation for the individuals impacted.

Also noted recently by Petryk et al. (2019), "emphasizing a specific minimum level of prenatal alcohol exposure for an FASD diagnosis is problematic" (p.7). Documenting the prenatal alcohol history, which is essential, is woefully lacking in many cultures where parental alcohol use in pregnancy is not routinely recorded in either pre or post birth records. It is without question, that a confirmed record of prenatal alcohol use is an essential component to a subsequent diagnosis. Again, with up to 90% of children and youth born of an alcohol exposed pregnancy not carrying identifying facial dysmorphic features, a record of exposure to alcohol while in utero is essential. The need for joined up thinking on the diagnosing of FASD is imperative within Irish culture. Again, collaborative efforts between agencies to define and approve a national diagnostic framework is warranted to ensure children are given correct and appropriate clinical interventions.

Service provision

Currently, a major impediment to service delivery for children, youth and their caregivers is the lack of FASD informed professionals. Evidence continues to emerge that knowledge and service provision in pre and post diagnostic services is still lacking in many parts of the world (Alexander et al., 2007; Coons et al., 2017; W. Curran, 2020; Mukherjee et al., 2015). Providing services to children with, or suspected of having, FASD is complex due to the multifaceted needs such individuals may have, as FASD is acknowledged to be ranging from mild to severe in the literature. Although significant empirical work has shown how FASD impacts state systems of care, little attention is given to the prevalence of FASD in our child welfare services. This has significant implications for social work services tasked with keeping children safe. As noted in Curran & Danbrook (2023b) social workers are in great need of specific supports and guidance in policy and procedure to meet the needs of this prevalence in child welfare structures. FASD prevention and service delivery work is complex on several levels. There are many different ideologies of how to approach 'prevention' of FASD within the many publications to date on the topic. Streissguth (1997) developed one of the most acknowledged strategies of a prevention model in her book, *Fetal Alcohol Syndrome - a guide for families and communities*. In this text, she talks of the five Ps of providing to families.

1. Public education
2. Professional training
3. Public Policy
4. Programs and Services

5. Parent and Citizen activism

What is very evident in 56 years of Fetal alcohol research, is the need of policy makers and allied health practitioners to make decisions informed by the best practice evidence where possible. Sadly, more often professionals turn to the easily accessible forums on social media as evidence to influence their decisions. These may not have academic rigor or even be the most up to date and approved evidence concerning fetal harm. As such, FASD education and knowledge translation needs to be taken hold of by state bodies of public health and social service at a professional level owing to concerns that the FASD dialogue is disseminating through social media (Mukherjee et al., 2015). As Domeij et al. (2018) explain, "the Province or State has substantial social, legal, financial and ethical interests in protecting children from the harm that results from the use of alcohol by their mothers during pregnancy, for the sake of the child and of the family" (p. 15). As such, leaving FASD to a social media narrative is to compromise the lives of individuals impacted, the caregivers struggling to care, and the allied health professionals operating under legal mandates to deliver service.

Again, an overarching public policy focus on addressing all strands of the FASD discourse is warranted. Through collaborative actions, all agencies should approach the development and implementation of services, so that FASD-informed programs can be developed, monitored, and evaluated to ensure compliance with best practice and ethical standards. It is important to acknowledge that FASD is not the preserve of any single agency, as the individuals living with or suspected FASD will span across all agencies of education, social services, criminal justice, addictions, and homeless services. To understand how FASD permeates all service structures of the state, a read of Streissguth et al.'s (1996) longitudinal study helps us to understand and see this pervasive disability and how it is currently impacting state systems of care.

The legal, ethical, and moral underpinnings of a policy focus

It is fully acknowledged in health care service delivery that ethics and ethical conduct are essential criteria in service provision. Health and social care practitioners must constantly weigh the rights of a pregnant women against those of her unborn child when dealing with concerns of alcohol use in pregnancy. In previous work by the author (L. Curran, 2007), where the focus was on wider substance abuse of both illicit drug and alcohol use in pregnancy, the study found a level of ‘palpable concern’ within health care professionals. Many such concerns are developed by the ethical and moral challenges that confront professional in-service delivery. Again, we have no shortage of materials to guide policy officers in addressing alcohol in pregnancy and FASD. Over the decades of fetal alcohol research, researchers have repeatedly highlighted the complex challenges that present in both the prevention of and management of FASD. Work by Bell et al. (2015), Boddy et al. (2010), Domeij et al. (2018), and Tortorelli et al. (2023) all offer evidence on the challenging and complex area that FASD presents in health care settings. Situating FASD policy of prevention and management will also need be cognizant of the legal status of the unborn, and how this status is balanced against the legal rights of motherhood. A recent publication by Malek (2017) looking at maternal decision-making and obligations during pregnancy across cultures is yet another offering of empirical evidence to help guide state actors in addressing the public health needs of maternal and child health. Indeed, cultural sensitivity needs to be a core objective of all those who seek to prevent and manage FASD, whether at the state level of policy formation or at the frontline of service delivery, implicit cultural understanding is essential. As noted by Kendall-Taylor & Fond (2017) "implicit cultural understandings challenge those working to increase public awareness and support for programs to prevent and address fetal alcohol spectrum disorder (FASD)" (p. 105). FASD is heavily situated and embedded within multiple cultural norms. As such, acknowledging cultural research and researchers is fundamentally important to achieving successful outcomes.

Conclusion

Ireland faces a mammoth task in preventing and managing FASD within its culture. Given the documented work of Irish epistemologists showing the high levels of alcohol use during pregnancy, it is evident that serious consideration needs to be adopted by all state agencies to combat FASD and its insidious impact on society. Despite a significant level of research activity concerning FASD, poor collective ownership of preventing and managing FASD exists within state systems of health and social care. The cost burden of FASD is again well documented globally. Such evidence should not be dismissed for a lack of cultural context. Currently, Ireland's FASD cost burden is unaccounted for, meaning such costs are being absorbed across multiple service structures without measurement. It is therefore of utmost urgency that Ireland adopts urgent prevention activities and improved assessment services. Situating FASD policy on prevention and management will also need be cognizant of the legal status of the unborn, and how this status is balanced against the legal rights of motherhood.

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