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Abstract

England now has a policy framework for Fetal Alcohol Spectrum Disorder (FASD). This proposes a suite of health care interventions, some of which attend to assessment and support for those who may be diagnosed with the disorder. Others, which are the focus of this commentary, have a stated goal of FASD prevention, to be achieved through embedding activities around alcohol abstention within maternity services and reproductive healthcare. Critical engagement with alcohol abstinence advocacy to pregnant women in this journal has linked this aspect of health promotion to larger debates about risk, moral panic, neoliberalism, self-surveillance and forms of citizenship. The new English policies on FASD have, however, been the subject of relatively little academic engagement so far. In this commentary, after an initial summary of points from the relevant literature in *Critical Public Health*, we take public debate about the new English policy as our point of departure, highlighting the precautionary approach, the emphasis on monitoring, and contraceptive advocacy for at-risk women. We suggest an important shift in English policy, from presenting women as managers of risk via self-surveillance, to positioning them as in need of routine management and 'other-surveillance' within healthcare systems. This raises more general questions about the meaning of 'autonomy' and 'support' in healthcare.

Introduction

Papers in *Critical Public Health* have set out a compelling critique of alcohol abstinence advocacy to pregnant women, linking this aspect of pregnancy to larger debates about risk, moral panic, neoliberalism, self-surveillance and forms of citizenship (Bell, McNaughton & Salmon, 2009; Leppo, 2012; Lupton, 2012; McCallum & Holland, 2008; Salmon, 2011). We take this critique as our starting point for this commentary about England's new policy framework on Fetal Alcohol Spectrum Disorders (FASD).

This framework is set out in documents published between 2019 and 2022, developed by the Department for Health and Social Care (DHSC), one of its then executive agencies (Public Health England, PHE), and the body responsible for developing evidence-based guidelines for healthcare provision (the National Institute for Health and Care Excellence, NICE). Titled 'Fetal alcohol spectrum disorder NICE Quality Standard' (NICE, 2020/2022), 'Maternity high impact area: Reducing the incidence of harms caused by alcohol in pregnancy' (PHE, 2020), and 'Fetal alcohol spectrum disorder: health needs assessment' (DHSC, 2021), these documents cross-reference each other and lay claim to a basis in evidence about the harms of the 'Alcohol Exposed Pregnancy' (AEP) (a term used to describe a pregnancy where a woman consumed any alcohol at any point). They prescribe expanded healthcare activities, some designed to assist in the diagnosis of, and response to, the disabling condition considered the possible outcome of an AEP, namely FASD, and others considered necessary for preventing AEPs through increasing rates of alcohol abstention.

While AEP prevention activities are familiar in other national contexts, they are newer for England, and the policy framework became the subject of public debate, particularly during the consultation on NICE's Quality Standard (bpas, 2020) and in the news media (Grover, 2020; Knowles and Gibbons, 2020). This debate focussed mainly on initial proposals from NICE to make the transfer of information about a pregnant woman's alcohol consumption to her child's health records automatic, with advocates for women's reproductive autonomy describing this as an infringement of medical confidentiality. More general objections were also raised, about insufficient concern for women's autonomy and about possible detrimental effects of increased surveillance of alcohol consumption in pregnancy for trust relations in healthcare.

These objections have, however, been the subject of relatively little academic engagement so far. Here, we therefore elaborate them, building on prior work in *Critical Public Health*. After initial comments drawing on this work, we take points raised by in public debate by the critics of the new FASD policy as our starting point. With reference to the text of the policy documents, we then elaborate three aspects of this criticism. The new policy framework, we conclude, presents greater routine monitoring of pregnant women by healthcare providers as necessary and so can be interpreted as making ‘other-surveillance’ central to efforts to increase rates of alcohol abstention. This, we suggest, raises questions of importance for pregnant women about the meaning ascribed to ‘autonomy’ and to ‘support’ in healthcare, which may have wider implications.

Contextualising English FASD policy

The concept FASD is central to the trajectory of modern policy responses around alcohol and pregnancy internationally. FASD is used as an umbrella designation (and in some national contexts as a diagnostic term) associating many developmental and health deficits with alcohol consumption during pregnancy. It is often described as vastly underestimated in prevalence and seriousness. Although it has been repeatedly clarified that there is no consistent evidence associating low levels of drinking with FASD, public health policy has come to respond by drawing on the terminology of ‘a precautionary approach’. Policy statements internationally frame FASD as serious and preventable, and opt to advise total alcohol abstinence, ‘based on limitations of the existing evidence and the impossibility of setting a ‘safe’ or ‘no risk’ level’ (McCallum & Holland 2018, p. 413). The concept ‘precaution’ has become primary in the policy response and increasing rates of alcohol abstinence is the policy objective. Thus, while US health authorities were the first to adopt a position of abstinence advocacy back in the 1980s, and commentaries have presented the US approach as an alarmist outgrowth of a particular history of moralism (Lowe & Lee, 2010), the norm has changed. Reflecting a perceived need for ‘awareness-raising’ about FASD, aspects of thinking familiar to the US have become apparent in policies elsewhere, promoting alcohol abstinence among not only women who are pregnant, but also those who could become so.

Engagement in *Critical Public Health* with this unfolding story of pregnancy, disability and policy responses has clarified much about it by relating abstinence advocacy to larger debates about risk, moral panic, neoliberalism, self-surveillance and forms of citizenship.

Public health messaging ‘that suggests that even one drink may be harmful’ has thus been described as akin to ‘moral panic’ which individualises disability and social problems and contrasted with initial research about Fetal Alcohol Syndrome (FAS) which emphasised wider factors in the development of impairments, for example nutrition and poverty (Bell et al. 2009, p. 158). Lupton also emphasised the individualisation of disability, arguing that social and cultural conditions have generated an idea of a ‘precious foetus’ set against the individual pregnant woman as the ‘carrier’, presented as paying insufficient heed to the advice of experts, causing health and developmental problems in the child (2011, p. 331). McCallum and Holland similarly consider the dominant discourse to be one that emphasises ‘individual responsibility of the mother, who is simultaneously the protector and greatest threat to the potential citizen’ (2018, p. 414).

One outcome discussed, considered characteristic of the US, is that drinking in pregnancy is designated a form of child abuse, pitting the rights of the woman against those of the fetus/child. Another is an expectation of self-surveillance and self-monitoring, and this has been presented as normative (Leppo, 2012). Lupton argued this expresses the wider tenets of 'neoliberal government', whereby '…citizens are expected to take responsibility for their own actions and welfare' and '…monitor, regulate and discipline their own bodies' (Lupton 2011, p. 335) but operates with especially powerful moralistic dimensions when the welfare of the child-to-be is presented as at stake. Lupton (2011) used the term 'reproductive citizenship' to describe this whereby, '…pregnant women are expected to engage in a bewildering array of risk-aversive behaviours to ensure the health and optimal development of their foetuses' (Lupton 2012, p. 330). Salmon's work, detailing policy responses to FASD in aboriginal communities, showed the limitations of neoliberal measures based on abstinence for those who need support most. 'The women most likely to have a child with FASD are those least likely to be able to reduce their alcohol use on their own in response to public health messages', she argued, and:

> [P]rimary prevention campaigns for FASD which increase knowledge about the harmful effects of alcohol on a foetus but are not directly coupled with the comprehensive support needed by those women most likely to be drinking alcohol while they are pregnant, may inadvertently increase their risks to maternal and child health by discouraging women from disclosing their substance use and pregnancies and seeking timely care (2011, p. 168).

This critique suggested policy that replaces risk reduction with abstinence promotion based on self-surveillance has serious deficits. An approach that looks to others to increase rates of alcohol abstinence (namely health care professionals and settings) has developed, however, and not only in North America. This modification to self-surveillance, and emphasis instead on ‘other-surveillance’ has, as we have noted, proved contentious. After a brief description of how this contention emerged in England, we elaborate on three aspects of it.

The new English FASD framework

As we have discussed elsewhere (Lee et al., 2022) the policy shift to abstinence advocacy in the UK began in 2007 and was strengthened in 2017, when the UK’s Chief Medical Officers (CMOs) decided to remove any remaining reference in advice to pregnant women to ‘a choice to drink’ and to what to do to ‘reduce risk’ (as previous guidance expressed it, limit consumption to ‘one or two units, once or twice a week’). In their justification for this change, the CMOs acknowledged absence of new evidence about harm caused by ‘low level’ drinking, but explained they favoured a combination of a ‘precautionary’ approach together with a preference for making advice ‘simple and clear’. The immediate background to the new English FASD policy lies in the approach then developed first in Scotland (Scottish Inter-Collegiate Guidelines Network (SIGN), 2019) which makes precautionary abstinence promotion not only a message to be acted on *by women*, but also part of healthcare provided *to women* before and throughout pregnancy (Lee et al., 2022). While the CMO’s precautionary stance at points proved controversial (Lowe & Lee, 2010), in contrast to the English controversy over this ‘other surveillance’ we describe here, there was little debate over the Scottish policy shift.

In England, strong support for policy change was offered by organisations who are part of the self-described FASD UK Community. This community is led by the National Organisation for Fetal Alcohol Spectrum Disorder (NOFASD), and made up of medical professionals specialising in FASD, and organisations for families mainly involved with adoptive or children's social care services caring for children who, often in the face of very difficult experiences with education and other services, have been diagnosed with FASD. Representatives from this community acted as informants and experts through the English policy development process and policy makers indicated the significance they attached to this interaction. The DHSC, for example, stated its document was written, '…following a series of roundtable events in 2018, between the Deputy Chief Medical Officer (DCMO), and policy makers from DHSC, experts and people with lived experience' (DHSC 2021, p. 3) and the appendix lists nearly 30 FASD advocacy groups. In turn, the new policy attention to FASD was described by NOFASD as 'a massive step forward' and the AEP prevention project, as it came to be formulated, presented as reflecting commitment to 'informed choice' and 'support' (NOFASD, 2022).

Others, working mainly in pregnancy advisory services, contested this interpretation, however, seeing the new policy as autonomy-reducing and threatening to supportive relations between women and healthcare professionals. Those who provide pregnancy advisory services were not defined as experts within the policy development process but rather exerted influence from the outside. As noted, this focussed particularly on the consultation on the draft of the NICE Quality Standard on FASD. The British Pregnancy Advisory Service (bpas) made a lengthy submission (bpas, 2020) questioning the proportionality and efficacy of monitoring all women during pregnancy for alcohol consumption and indicating the pitfalls of continually questioning women and recording information. Media comment was, in turn, generated about the perceived deficits of greater surveillance and recording of alcohol consumption during pregnancy (Grover, 2020; Knowles and Gibbons, 2020).

Hostility to this questioning of the direction of policy has been expressed. Sandra Butcher, CEO of the NOFASD, warned of the need to, ‘beware of specialist interest groups’ who are ‘twisting this narrative about the risks of alcohol in pregnancy’, and of ‘FASD deniers saying there isn’t enough evidence’ (NOFASD, 2022). Acrimony has been, in this way, an aspect of the policy process, but we suggest the disagreements raised have posed an important set of questions which form the point of departure for the rest of this commentary. We highlight three areas which capture the main themes of the criticisms made during the consultation on NICE’s Quality Standard (bpas, 2020) and in newspaper reporting (Grover, 2020; Knowles and Gibbons, 2020). These are: 1) the emphasis via precautionary thinking on ‘clarity’ expressed in the message ‘no alcohol’; 2) mandatory collection and recording of information about alcohol consumption; and 3) inclusion of FASD prevention as part of family planning services. We elaborate them with reference to the wording of the texts of the policy framework as a whole (DHSC, 2021; NICE 2020/2022; PHE, 2020).

Problems of the new FASD framework

1. *Is ‘clarity’ best?*

The need for ‘consistency’ and ‘clarity’ in messages about abstinence underpin the FASD policy; acknowledgement of any ‘uncertainty’ about the relation between alcohol and FASD is presented as at best unhelpful, and at worst dangerous. Overall ‘the importance of consistent messaging’ is thus described by the DHSC the ‘policy priority’ with emphasis placed on, ‘advocacy groups raising concern around the length of time the CMO’s advice did not align with that from NICE’ (DHSC, 2021, p.9). The Quality Standard (QS) from NICE, however, is now not only ‘aligned’, but goes well beyond ‘consistent messaging’, defined as providing information to pregnant women about the recommendation to abstain. NICE’s QS comprises five statements. The first two are about ‘the pregnant woman’ and abstinence advice is described as an ongoing throughout the *duration* of pregnancy. Statement 1 is, ‘Pregnant women are given advice *throughout pregnancy* not to drink alcohol’, and further, ‘Midwives and other healthcare professionals should give women clear and consistent advice on avoiding alcohol *throughout pregnancy*’ (2022, p. 5, our emphasis). PHE has recommended ‘personalised care responses’ and, adopting the slogan of NOFASD, stated ‘personalised care’ starts from the proposition, ‘There is no safe time or safe amount of alcohol to drink during pregnancy’ (2020, p. 7) and that ‘pregnancy provides a key opportunity to raise awareness and prevent harm’ (2020, p. 9). Professionals are instructed to avoid discussing any uncertainty in evidence in favour of giving ‘consistent messaging’, taking the ‘opportunity’ to alter women’s risk-perception about alcohol, and to do so throughout pregnancy.

For its critics, this interpretation of uncertainty raises long-standing questions of paternalism (assuming discussing complexity in evidence should be avoided) and sexism (adopting an approach that departs from what would be usual because of a sex-based capacity for pregnancy) (Gavaghan, 2009), and also concerns about the anxiety-provoking effects of associating *any* alcohol consumption with impaired fetal development. Yet only the DHSC’s document mentions claims made by those working in pregnancy advisory services about possible harms of the idea that *any* prenatal alcohol consumption may damage a fetus, when noting, in a short section on law and ethics that, ‘raising awareness of the potential harms of alcohol consumption during pregnancy would mean some women may feel pressures to terminate a pregnancy even if the risks were extremely low’ (DHSC, 2021, p.37). We now turn to criticism of the outcome of this definition of precaution, expressed in concerns about on-going surveillance and monitoring of women during pregnancy.

2. *Other-surveillance and the question of autonomy*

Definitions of professional responsibility that include not only ongoing *discussion* about the need for abstinence, but also *monitoring and recording* of women's alcohol consumption have been a focus for criticism. NICE's second Statement in its Quality Standard is on 'Fetal alcohol exposure', prescribing pregnant women, '…are asked about alcohol use' (rather than given information they may act on); that this must happen 'throughout pregnancy'; and that 'this is recorded' (NICE, 2022, p.8). Recording in maternity notes, it is specified, should detail 'the number and types of alcohol drinks consumed, as well as the pattern and frequency of drinking' (NICE, 2022, p. 10). PHE stated, 'frontline professionals' should, 'record alcohol intake throughout pregnancy, not just at booking appointment' and 'make every contact count in terms of encouraging women abstain from alcohol use during pregnancy and where necessary referring to further, specialist support' (PHE, 2020, p. 10).

There is no consideration of the difference from prior recommended practice, using questionnaire-based 'screening tools' such as AUDIT-C which aim to capture information about drinking at 'risky levels', and monitoring *all* drinking and *all* women. Instead, documenting alcohol use in maternity records routinely is justified primarily as part ongoing professional encouragement of abstinence. Increasing rates of abstinence becomes the objective, and responsibility for this outcome shifts from the woman, and her self-surveillance, to the healthcare professional.

The DHSC discusses the perceived deficits of ‘merely providing information to an individual’ and the advantages of such routine surveillance in accordance with theories about the limits of individual choice: ‘…a person’s freedom to make choices is often affected, constrained or ‘determined’ by a host of other social factors outside of their control’ (DHSC, 2021, p.23). The DHSC’s text suggests that professional-led monitoring can, ‘…enhance the autonomy of an individual and increase the chance of an intervention bringing about a positive change in their life’ (DHSC, 2021, p. 23). Yet problems with this idea of how autonomy is enhanced, such as the possibility that this approach might have the *opposite outcome* and make women *most* likely to be consuming alcohol at high levels even *less* likely to access support because of a fear of professional surveillance, are not discussed; documents consider only speculative benefits. No recognition is given either to the possibility that there may be multiple reasons why a woman might consider occasional drinking valuable, and place importance on others’ recognition of this. Her autonomy is defined as only contingent on the work done by professionals to alter her perceptions and ensure she makes ‘a positive change’.

Mechanisms for accurately ‘ascertaining the risk of alcohol exposure’ constitute the other focus for concern with information recording. Alternatives to asking women discussed include the possibilities of ‘biomarkers’ (listed to include imaging techniques, and meconium or cord blood assessment). Despite documented concerns in the relevant literature (Marcellus, 2007) and efforts made during the policy development process to raise them, there is scant reference to any downsides to such new forms of assessment. The DHSC’s is the only document to make any reference to pitfalls when it notes, ‘…distinct ethical challenges’ (DHSC, 2021, p.38). There is no elaboration of these challenges, however, and no discussion in relation to the pregnant woman of the terms ‘patient benefit’ and ‘consent’ usually considered inherent to any screening programme. To the contrary, 'effective service delivery' should, 'determine true prevalence rates through research into effective antenatal alcohol screening tools, blood biomarkers, meconium testing and so on' stated PHE (2020, p. 12).

3. *Pregnancy planning, contraception and pregnancy prevention*

'Women planning a pregnancy' and 'pregnant women' have been given the same advice, 'avoid alcohol', since well before publication of the new FASD policy. Debate has continually attended this expansion of abstinence advocacy for unduly limiting women's lives, given the different biological states involved for women who are, and who are not, pregnant. This advice is reiterated, however: 'all women trying to become pregnant' should be advised by 'frontline healthcare professionals', 'that the safest approach is not to drink alcohol at all' (PHE, 2020, p. 10). There is additional blurring of distinctions between pregnancy and its absence, however, in a new way, in PHE's use of the term 'preconception health', of which FASD prevention is said to form one part. This term is used without any reference to contest over the idea that non-pregnant women should ideally abstain and be 'pregnancy ready'. In the Foreword to PHE's document, Prof Viv Bennett, Chief Nurse and Director, Maternity and the Early Years, situates abstinence advocacy as part of a general drive to, '…. increase action…from preconception through to 6 to 8 weeks postpartum' and 'ensure *every woman* is fit for and during pregnancy and supported to give children the best start in life' (2020, p.3, our emphasis).

The linking of any alcohol consumption to pregnancy prevention has also been specifically questioned by those who provide contraception and abortion services. Disagreement attends the proposition that, 'FASD prevention should complement public health approaches to family planning and contraception' (DHSC, 2021, p. 19) and that, '…health professionals can *take the opportunity…*to raise the issue of contraception and family planning with *all women of childbearing age*, and make clear the links between alcohol, sexual activity and FASD' (DHSC 2021, p. 25, our emphasis). The terminology of 'empowerment' is used to describe this idea of routine interactions in family planning services (DHSC, 2021, p. 25) but subsuming contraceptive provision to objectives other than those expressed by the woman concerned is not in line with understandings of empowerment held by its critics.

Targeted interventions are proposed alongside universal contraceptive services. PHE instructed local authorities to:

> Commission services to deliver interventions to women who are not pregnant but at risk of an alcohol exposed pregnancy i.e. using alcohol and not using effective contraception (PHE, p. 11).

Long-Acting Reversible Contraceptives (LARCs) are mentioned most often as the favoured solution to address the risk of alcohol-exposed pregnancy. PHE stated, 'effective service delivery' should: 'Increase postnatal access to long-acting reversible contraceptives (LARC)' (PHE, 2020, p. 12). Problems with targeting marginalised groups for LARC provision noted in the relevant literature (Lowe & Rowlands, 2022) are not mentioned by PHE. The DHSC approvingly discusses a programme titled 'CHOICES', which is described as, 'a behavioural intervention for women who are not pregnant but are at high risk for an alcohol-exposed pregnancy (AEP)' and explains 'it uses motivational interviewing' and 'cognitive behavioural strategies', 'to increase women's motivation and commitment to change' and so agree to use a LARC (DHSC, 2021, p. 25-26). Although it has been argued this approach can value women’s autonomy, there is no mention of whether contraceptive provision, in this iteration, is defined as means to reduce rates of AEPs, rather than enable a woman to achieve outcomes she considers to be those she wants.

Concluding points

FASD is a serious, lifelong disability and the needs of those who may be diagnosed with it, and their families (mainly people managing the demands of adoption and the children’s social care system), are considerable. Yet the critiques published in *Critical Public Health* of alcohol abstinence advocacy to women as central to a response to FASD have shown that precautionary thinking expressed in support for alcohol abstinence, rather than risk reduction, should not be accepted as benign. They have made the important contribution of relating it to larger debates about neoliberalism and self-surveillance that inform much critical engagement with behaviour modification efforts within public health more widely.

The contest around the recent development of English FASD policy elaborated in this commentary has, we suggest, raised valid objections that deserve ongoing attention, about the move to supplement self-surveillance with greater ‘other-surveillance’. These demand greater consideration of whether ‘clarity’ is better than the veracity of acknowledging uncertainty, of the problems of building increased monitoring and new forms of alcohol screening into maternity services, and of the linking of alcohol abstention promotion to family planning services.

We conclude that ongoing greater scrutiny of the new response to FASD is warranted. This is because of the important questions that have been raised about women’s healthcare, but we also suggest a more general question is raised by this example about the relation between ‘self’ and ‘other’ surveillance’. This asks whether greater intervention by healthcare professionals does, as is claimed, enhance autonomy, and this sense, the trajectory of this policy area may raise questions relevant to efforts to modify health behaviour more generally, as part of shifts in neoliberal health policy.

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