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## Is it FASD? And does it matter? Swedish perspectives on diagnosing fetal alcohol spectrum disorders

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### ABSTRACT

Fetal alcohol spectrum disorders (FASD) is an umbrella term covering a range of conditions related to prenatal alcohol exposure. In Sweden, only the most severe of these conditions, Fetal alcohol syndrome (FAS), is used as a medical diagnosis. The aim of this study was to analyze the Swedish discussion on whether or not FASD conditions (other than FAS) should be actively diagnosed/identified. The data consisted of a webpage material from a FASD interest organization and a report from a Swedish authority. The analysis was informed by Fairclough's critical discourse analysis and strived to pay attention to which discourses that were drawn upon, and how these discourses related to each other, and to a broader social context. The discussions on whether or not FASD should be actively diagnosed/identified were structured by three main discourses. These were: a scientific discourse, a pragmatic discourse, and an ethical discourse, with the scientific discourse taking a special position, often being present also when other discourses were drawn upon. Taken together, there is not yet any consensus around what the status of the FASD conditions should be in Sweden, neither regarding the usefulness of diagnosing/identifying, nor regarding the causality between prenatal alcohol exposure and FASD.

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### Introduction

During the last decades, there has been an increase in psychiatric diagnosing of children in general. The reasons for this increase are a highly debated topic. Some relate it to a broadening of diagnostic criteria, but also to how both lay people and professionals have gained a heightened awareness of neuropsychiatric difficulties among children (Atladdottir et al., 2015). Other have expressed worries that increased psychiatric diagnosing of children reflects a tendency in contemporary society to reduce human behaviors and difficulties to neurobiological functions in a way that ignores children's emotional experiences and social contexts (Erlandsson & Punzi, 2017), and that it serves the function of medicalizing childhood (Pawluch, 2003). Psychiatric diagnosing of children is thus not an uncontroversial phenomenon.

Taking its point of departure in a social constructionist perspective, viewing our understanding of problems as shaped by their social, political, and cultural contexts (Loseke & Best, 2003), this study will focus on the Swedish discussion on whether or not the psychiatric conditions included in the term Fetal Alcohol Spectrum Disorders (FASD) should be established as formal psychiatric conditions in Sweden. This discussion can be placed within two broader discursive contexts. The first is the one mentioned above, that is, how the increased neuropsychiatric diagnosing of children should be defined, explained, and valued. The other discursive context is the general discussion on harm due to prenatal alcohol

exposure, and the related discussions on the state of the evidence, and on what should be considered the proper recommendations, and the reasonable actions taken, within this area.

FASD is an umbrella term covering both the quite well-established diagnosis Fetal Alcohol Syndrome (FAS) but also other, milder forms of conditions related to prenatal alcohol exposure. The term FAS was first coined in 1973 as 11 unrelated children, all born to women with heavy alcohol problems, were found to have the same specific pattern of minor facial malformations, and later also turned out to have delays in their intellectual, social and motor developments (Jones & Streissguth, 2010). The prevalence of FAS seems to vary considerably between countries, but also with research method and diagnostic criteria used (Burns et al., 2013; May et al., 2009).

When it comes to all types of diagnoses included in FASD the incidence is supposed to be considerably higher than that of FAS. At the same time, the causal link between prenatal alcohol exposure and the FASD conditions is disputed (e.g. Miller, 2013). This scientific uncertainty has led to differing perspectives on whether the FASD diagnoses should be used. Some scholars emphasize this as a necessity in order to guarantee the right help and support for the children in question (Loock et al., 2005), while some have argued that the FASD diagnoses are too broad and unspecific to give any real guidance for treatment or intervention (Price & Miskelly,

2015). Still others have claimed that the risks connected with prenatal alcohol exposure have been exaggerated in a way that reminds of moral panic (Armstrong & Abel, 2000), and that women already marginalized are further exposed to negative consequences of this moralism (Bell et al., 2009).

A couple of studies have explored the development of the FASD diagnoses from a social scientific perspective (Armstrong, 2003; Armstrong & Abel, 2000; Golden, 2005). For example, Armstrong (2003) has shown how the establishment of the FAS diagnosis in the 1970s was followed by a diagnosis expansion, where more and more, sometimes quite diffuse, symptoms in children came to be defined as related to fetal alcohol exposure. Armstrong argues that this process was in part driven by medical experts with a vested interest to '...claim authority to contribute to knowledge and research on the new syndrome' (p.86). When fetal harm due to alcohol begun to be seen as ranging from mild to severe abnormalities, this also changed the definition of risky drinking during pregnancy – from heavy drinking to all forms all alcohol consumption. As a result of this, drinking during pregnancy increasingly became framed as a public health problem (Armstrong & Abel, 2000). Another aspect of relevance is how the pregnant woman and the fetus, much due to medical discoveries and progress during the last fifty years, have gone from being viewed as a single entity to being defined as two separate individuals with their own, sometimes conflicting, needs (Armstrong, 2003). This view, implying that the pregnant woman constitutes a potential risk to her fetus, has been described as causing punitive attitudes and laying the ground for coercive measures towards pregnant women who drink alcohol (see e.g. Leppo, 2012). In a couple of US states, women have been arrested and charged for drinking during pregnancy, mainly during the 1980s and 1990s (Golden, 2005), and also in Sweden proposals of coercive care for pregnant women with risky drinking, or consumption of illegal drugs, have been discussed (Stenius, 2009) but turned down.

Furthermore, Lowe et al. (2010) have showed how FASD has aroused increasing concern in UK media during the last decades. They argue that this concern is not mainly a consequence of new evidence, but rather related to contextual factors, like the emergence of FASD interest organizations and prevailing ideals of responsible mothering being extended to also include pregnancy.

To date, there is no consensus around whether there are any 'safe' level of drinking during pregnancy. There are also variations between countries in how risks connected to drinking during pregnancy are interpreted, and what efforts are taken in order to prevent FASD (Drabble et al., 2011). Several countries, Sweden included, have recommendations formulated from a precautionary principle, ascribing total abstinence from alcohol during pregnancy. These recommendations have, however, been criticized for being contradictory (Leppo & Hecksher, 2011), and to lack an evidence base (Lowe & Lee, 2010).

However, while social scientific research has explored the development of the FASD diagnoses, as well as policies of alcohol consumption during pregnancy, there is a lack of research on how the benefits and drawbacks for individual children and their families of being diagnosed with FASD

have been discussed in the processes of formally establishing these diagnoses. In the study at hand my aim is to shed light on these aspects of the process.

Hitherto, in Sweden, only FAS is used as a medical diagnosis. This is a difference from some other countries, for example the United States and Canada, where FASD conditions other than FAS have been actively diagnosed/identified since the early 2000s (Chudley et al., 2005; Hoyme et al., 2016). In a Swedish context, it is thus not given to understand and categorize difficulties and disabilities of prenatally alcohol exposed children as FASD. In this study, the Swedish discussion on whether FASD conditions should be actively diagnosed/identified will be analyzed with a focus on how two central social actors, one authority and one interest organization, have presented their perspectives on the subject.

## Aim of the Study

The aim of the study is to analyze the Swedish discussion on how FASD should be defined and whether FASD conditions (other than FAS) should be actively diagnosed/identified. More specifically, the focus will be on which arguments for and against diagnosing/identifying FASD conditions that have been presented by the Swedish authority SBU (Swedish council for health technology assessment) and by a Swedish interest organization named the FAS-organization. The discussions on FASD, analyzed here, can thus be seen as a case study of how psychiatric diagnoses in general are negotiated and agreed upon, through processes where different claim-makers with different understandings, values and beliefs are involved (Jutel, 2009). At the same time, the case of FASD stands out from other psychiatric diagnoses, as the term FASD emphasizes the cause (the biological mother drinking alcohol during pregnancy) of the symptoms, rather than the symptoms themselves (Price & Miskelly, 2015). As the FASD diagnoses are not uncontroversial, this will give an opportunity to study how arguments for and against using the FASD diagnoses are built up, how different aspects are weighed against each other, and in which ways the uncertainty of the scientific basis of these discussions is handled. With a focus on discursive aspects, the study at hand will give an insight in the not yet finished process of, maybe, establishing FASD as a formal condition/diagnosis in Sweden.

## Background

### *Fetal alcohol spectrum disorders*

FASD (Fetal Alcohol Spectrum Disorders) is an umbrella term which includes FAS but also other, less severe, birth defects and brain damages with suspected connection to alcohol consumption during pregnancy. The term FASD and its associated conditions (additional to FAS) have been used since the early 2000s. Beside FAS, FASD includes pFAS (partial Fetal Alcohol Syndrome), ARBD (Alcohol-Related Birth Defects), and ARND (Alcohol-Related Neurodevelopmental Disorder)/ND-PAE (Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure). pFAS can be used when some, but not all, of the

criteria of FAS, are fulfilled. The minor facial malformations are however required (Manning & Hoyme, 2007). ARBD can be used when children are born with different types of physical malformations and there is a confirmed prenatal alcohol exposure, while ARND is possible to use when children have intellectual delays or behavioral problems, and prenatal alcohol exposure is confirmed (ibid). ND-PAE was included in the 2013 year update of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM 5) as a condition for further study, and is focused on behavioral problems and impaired cognitive functioning (Doyle & Mattson, 2015). As should be evident from the description above, the variation in symptoms between, and within, the different FASD conditions is broad. Furthermore, several diagnostic guidelines for how to identify the FASD conditions exist. Specific criteria and cut-offs vary across these guidelines, and this lack of standardization may cause uncertainty in research results as well as in clinical practice (Brown et al., 2019).

In the following, when the term FASD is used in this article, it refers to the conditions above, FAS excluded.

A broad range of harm has been connected to prenatal exposure to alcohol. Studies have shown that children who have been exposed to alcohol during pregnancy, can be suffering from a range of cognitive and behavioral impairments. Examples include deficits in motor skills, problems with attention, language problems, impaired executive functions as well as impaired memory functions and learning difficulties (Mattson et al., 2019). The group has also been shown to have a heightened risk of psychiatric problems in early adulthood (Barr et al., 2006). Furthermore, FASD has been described as connected to several medical conditions, such as heart defects, kidney failure, hearing loss and epilepsy (see e.g. Jonsson, 2019).

However, there is a lack of agreement on the prevalence of FASD. While a prevalence of 1 in 100 live births is a number often mentioned (Jonsson, 2019; Manning & Hoyme, 2007) single studies have shown rates as high as up to 4.8% in a US context (May et al., 2014) and 6,3% in areas of central Italy (May et al., 2011). Furthermore, prevalence rates have been shown to vary according to research method used (May et al., 2009). A complicating factor when estimating prevalence is that the symptoms of the FASD conditions are partly overlapping with those of other diagnoses, like ADHD (Attention-deficit hyperactivity disorder). There is a high co-morbidity between FASD and ADHD (Rasmussen et al., 2010), in a study by Clark et al. (2004) as high as 65%. And while some researchers argue that the FASD conditions are often misdiagnosed as other neuropsychiatric conditions (Chasnoff et al., 2015), others have expressed concerns that children with other neurodevelopmental problems, but who have also been prenatally exposed to alcohol, run the risk of receiving false positive FASD diagnoses (McLennan & Braunberger, 2017).

### ***The link between prenatal alcohol exposure and the FASD conditions – is it causal?***

The question whether there is a causal link between low to moderate prenatal alcohol exposure and the conditions of FASD is disputed. Some researchers are definite that these conditions are caused by prenatal alcohol exposure (see e.g.

Roozen et al., 2018). Others emphasize that based on current knowledge, prenatal alcohol exposure can only be defined as a risk factor (and not as the cause) for the FASD conditions. For example, Miller (2013) underlines that the fact that prenatal alcohol exposure is associated with neurological harm does not mean that this outcome would not have occurred in a specific individual if there had been no prenatal exposure to alcohol. Furthermore, since the existing scientific literature is too heterogeneous in how alcohol consumption is measured, it has not been possible to compile meta-analyses on how specific maternal drinking patterns are related to the FASD conditions (Roozen et al., 2018). In addition to this, there are several difficulties connected to documentation of prenatal alcohol exposure, such as retrospectively collected data, tendencies of mothers to underreport alcohol consumption during pregnancy due to stigma, and also the fact that many of the children in question are adopted or in foster care (Price & Miskelly, 2015). To further complicate the picture there is also a range of other factors that have been pointed out as moderating the negative impact of prenatal alcohol exposure. Besides quantity, frequency and timing of drinking, the mother's age and the number of earlier pregnancies and births, as well as her body size, nutrition and socioeconomic status have turned out to be modifiers of risk (May & Gossage, 2011). Furthermore, some studies suggest that the dimension of epigenetics should be of relevance for the FASD conditions (Resendiz et al., 2013). Biological, environmental and social factors thus seem to interact in complex ways (Meurk et al., 2014).

## **Theory and method**

### ***A sociological perspective on diagnoses***

Theoretically, the study takes its starting point in a social constructionist perspective, sharing the view that the way we think and speak about a specific problem has far-reaching consequences, sometimes even more far-reaching than the objective characteristics of this problem (Loseke & Best, 2003). More specifically, the study is inspired by a sociological perspective on diagnoses. This means that the establishing of a medical diagnosis is not only seen as an act of identifying and naming an objective state of illness. It is also a process in which a specific diagnosis has to be negotiated and agreed upon, and where several claims-makers and, sometimes competing, interests can be taking part (Conrad & Barker, 2010; Jutel, 2009). According to Jutel (2009, p. 278), a diagnosis organizes illness as it is 'identifying treatment options, predicting outcomes, and providing an explanatory framework'. Furthermore, a diagnosis not only works as marking the line between what should be considered normal and what should be seen as requiring treatment; for the individual it can also be crucial in qualifying for things like expensive medications, sick-leave and access to support groups (ibid).

### Critical discourse analysis

Methodologically, the analysis was informed by the basic principles of critical discourse analysis. According to Fairclough (2010) the goal of critical discourse analysis is to analyze and clarify the relations between discourse and other elements of social processes. An important theoretical point of departure is that language is produced by existing structures, but at the same time can work in ways that reinforces or changes these structures. In order to facilitate an analysis that pays attention to these mechanisms, Fairclough (1992) has developed a three dimensional model. At the first level, the focus is on the text. Here, the analysis centers on concrete linguistic devices, like choice of words, use of metaphors, modality and transitivity. The term modality denotes the degree of certainty and determination with which a statement is made, while transitivity concerns how actions are described to be performed, that is who did what, and with which degree of agency. On the next level, called the discursive practice level, the analysis focuses on how the production and consumption of a text is dependent on and related to already existing discourses. On the third level, the social practice level, the discursive practice is connected to a broader context, often through the use of relevant sociological theories (ibid).

In line with Fairclough's thoughts referred to above, 'discourse' is in this study seen as carrying representations of both material and ideational aspects, and functioning as both constitutive and constituted by its social context. In order to identify the discourses structuring the discussions of diagnosing/identifying FASD, those parts of the material that was relevant to the aim of the study were selected and carefully read several times. In an initial stage, I identified which arguments for and against diagnosing/identification that was presented in the materials, and when doing this, attention was paid to choice of words, modality and transitivity (Fairclough, 1992). In the next step, attention was paid to what logics and rationales that were underlying the statements. In this way, a *scientific*, a *pragmatic*, and an *ethical discourse* were identified. Typical of claims made within the scientific discourse were phrases like 'research has shown...' or statements that research does not give any 'clear answers.' It should be emphasized that I have not evaluated whether those arguments and statements categorized as drawing on a scientific discourse are 'truly' scientific in how they use and refer to existing research in this area. The label scientific discourse rather refers to how arguments are build up and legitimized with reference to research. Significant for the pragmatic discourse was its focus on usefulness. Statements and arguments made often emphasized practical aspects, such as the diagnosis' potential of 'making it [everyday life] easier' for the child and its family, or doubts about the diagnosis being of 'any use' in clinical practice. The ethical discourse, finally, was at use when consequences of diagnosing/identification were discussed. The statements/discussions drawing on this discourse were many times hypothetical, and using formulations like 'there is a risk that...' and 'this can lead to...'

When paying attention to the discursive practice level the focus was on how the discourses identified interacted with each other. In order to connect the discursive practice to the broader social practice, the results of the analysis were related to the theoretical perspective on diagnoses described above and to surrounding social factors of relevance.

### Data

The data analyzed in the study consist of two different text materials. Regarding the aspects of production and consumption (cf. Fairclough, 1992), it is important to note that the two texts are produced in different contexts, with different aims, and directed to (at least partly) different text consumers. The first text is a report from the Swedish authority SBU (Swedish council for health technology assessment), named *Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Spectrum Disorders (FASD) – Conditions and Interventions*. SBU is an authority that evaluates methods used by medical and social services, and their assessments are based on systematic literature reviews of published research. The other material is retrieved from the webpage of a Swedish interest organization called the FAS-organization (<https://www.fasportalen.se/>). The FAS-organization is a non-governmental interest organization with members who are parents or relatives of individuals with FASD, or persons who have FASD themselves. The question of whether or not to diagnose/identify FASD is one of the main focuses of the over 250 pages long report from SBU. Also on the webpage of the FAS-organization the question of identification/diagnosing is recurrently touched upon, especially in those parts of the material directed towards professionals within health care, schools and social services. The quotes presented in the results section below are translated from Swedish to English.

The choice of these two materials for the analysis became natural since they were the only found in my search for public text materials that discussed the question of whether or not to diagnose/identify FASD in Sweden. While the broader question of alcohol use during pregnancy has been more widely debated in Sweden, the specific question of diagnosing/identifying FASD has been considerably less acknowledged.

### The report

The SBU-report on FASD conditions was carried out on directive of the Swedish government, as The National Board of Health and Welfare had earlier pointed out children with prenatal exposure to alcohol and drugs as a neglected group (Government Decision, 2015). In order to acknowledge the perspective of individuals with FASD conditions, and their relatives, the authors of the report also cooperated with the FAS-organization (the organization from whose webpage the rest of the material analyzed in this study is retrieved). In the report a short chapter presents the perspective of individuals with FASD and their relatives, studied through survey responses. Representatives of the organization also took part in a reference group, listed in the report's appendix section. The level of intertextuality (cf. Fairclough, 1992) between the

two materials can thus be defined as relatively high. However, only a few aspects of the FAS-organization's chapter are picked up in the final discussion and conclusion sections of the report. The aim of the SBU-report was to evaluate whether the wellbeing and social situation of children fulfilling the criteria of FASD conditions, and their families, can be expected to improve if the children in question have their conditions formally identified/diagnosed. In order to answer this question the report focuses on two sub questions. The first one is what consequences the FASD conditions have for the children in question, for their families and for society. The second sub question is what effects there are of interventions for children fulfilling the criteria for FASD conditions. As the aim of this study is to analyze the discussion on how FASD should be defined and whether the FASD conditions should be actively diagnosed/identified the focus of the analysis has been restricted to those parts of the report where these aspects are discussed.

### *The webpage material*

The Swedish FAS-organization is an interest organization that offers information on FASD, support for families with children with FASD conditions, arranges member meetings, courses and lectures, and carries out opinion forming in order to raise the awareness of FASD. The FAS-organization is connected to similar organizations in other countries through the European FASD Alliance, and can be seen as one of the most influential social actors concerning FASD in Sweden. On their webpage ([www.fasportalen.se](http://www.fasportalen.se)), the FAS-organization provides links to research in the area, and they have financial support from The Swedish National Board on Health and Welfare. The material analyzed in this study has been retrieved from the FAS-organization's webpage. A substantial part of the webpage material consists of information directed to professionals within child care, schools, health care and social services. For example these groups are approached through a number of information sheets for downloading, directed at each group of professionals separately. These information sheets consist of descriptions of the conditions and underline the importance of children showing symptoms of FASD conditions being identified and getting adequate support interventions. On each of these sheets, there are also pictures of children's faces that are to varying degrees displaying those minor facial malformations typical of the FAS condition. Of interest for the analysis has also been the information campaign '1 out of 100,' which was launched in 2019, and aimed at raising the awareness of FASD among professionals within the Swedish child health care. As with the report from SBU, those parts of the webpage text materials that discussed definitions of FASD and the advantages, or disadvantages, with diagnosing/identifying FASD conditions were selected for the analysis. The material analyzed was retrieved during November 2019.

Taking aspects of text production into consideration, it is important to acknowledge the different positions from which these text materials are made. The webpage material is formulated by members of an interest organization, of whom many have their own experiences of the problems described.

The report, on the other hand, is formulated by experts working for an authority with high scientific status. Thus, the SBU report, made by an authority on directive of the government, naturally can be expected to have a greater direct influence on future decisions made in the area than the texts on the webpage of the FAS-organization. However, the impact of the FAS-organization should not be underestimated as they reach out to both professionals and the public, and thus may reach groups that do not come in contact with the SBU-report.

## **Results**

Through analyzing the SBU report and the webpage material with a focus on definitions of FASD and which advantages, and disadvantages, of actively diagnosing/identifying FASD that were presented, three discourses were identified as structuring for these discussions. These were: a *scientific discourse*, a *pragmatic discourse*, and an *ethical discourse*. As will be seen below, these discourses are to varying degrees connected to each other, and also to other broader discourses and material circumstances of a wider social context.

In the SBU report, both the terms identification and diagnosing are used. The FAS-organization does not explicitly argue for the FASD conditions to be established as a formal medical diagnosis. Instead, they emphasize that the difficulties experienced by the children in question should be actively identified through professional assessment and understood just as FASD-related, and not as anything else. However, as the term identification refers to a medical assessment aimed to find out whether the difficulties of an individual are alcohol related or not, the difference between identifying and diagnosing does not appear to be crucial.

### *The scientific discourse. What do we (not) know?*

The *scientific discourse* is mainly drawn upon when the causal relation between prenatal alcohol exposure and the FASD conditions is discussed, but it is also present when the existence of effective interventions is brought up. Regarding the question of causality, there is a focus on *lack* of evidence, and both the SBU and the FAS-organization struggle to position themselves in relation to scientific uncertainty in the area.

In the introduction of the SBU-report, the authors clearly underline that they will neither discuss the prevalence of FASD nor the question whether the link between prenatal alcohol exposure and the FASD conditions should be considered causal or not. This leads to a quite vague use of language when the term FASD is presented:

Fetal alcohol spectrum disorders (FASD) is a disputed term which includes the spectrum of birth defects that might be caused by the mother consuming alcohol during pregnancy (SBU, 2016, p.7).

Concerning the modality of the quote above, it is notable how the word 'disputed' functions as a way for the SBU to distance itself from an unreserved acceptance of the term FASD. Also through the word 'might' the degree of modality is drastically lowered. This could be seen as a way to clarify

the report's scientific stance, claiming a position of objectivity in relation to the complicated state of the evidence.

The decision of the SBU not to take a stand in the question of causality between alcohol exposure and FASD also results in sometimes lengthy formulations. Instead of writing 'individuals with FASD' the definition 'individuals fulfilling the criteria for conditions within FASD' is used:

This assessment focuses on individuals fulfilling the criteria of conditions within FASD. SBU does however not take a stand in the question whether the disabilities described are caused by exposure to alcohol or by other, or interacting, factors (SBU, 2016, p.8).

A scientific discourse is also clearly present in the webpage material as the FAS-organization makes efforts to account for the complex question of causality. Regarding transitivity, the formulations in the quote below imply a causal relation between prenatal exposure to alcohol and FASD:

Fetal Alcohol Spectrum Disorders, FASD, is the umbrella term for those harms that can be seen in children prenatally exposed to alcohol (FAS-organization, 2019c).

However, this indirect statement of causality is at other places in the webpage material partly nuanced, as co-existing factors, as well as the possibility that drinking during pregnancy does not always result in FASD conditions, is recognized:

There are several reasons why some children make it through [an alcohol exposed pregnancy] without getting harmed, while others don't. It depends among other things on how much the mother has drunk, at what time during pregnancy, and in which way – a continuous intake of small amounts or occasional binge drinking. It also depends on the general health of the fetus and its genetic capability to handle toxic substances, as well as on the health and well-being of the mother. Other relevant factors are malnutrition, environmental toxins, smoking, medications, drugs, etc (FAS-organization, 2019f).

Thus, when discussing the nature of FASD it is clear that the SBU displays ambivalence towards the use of the term FASD in a way that the FAS-organization does not. When it comes to the causal relation between prenatal alcohol exposure and FASD, the SBU explicitly states that they will not take any stand in the question, while the FAS-organization communicates the view that FASD conditions are caused by drinking during pregnancy, but that drinking during pregnancy does not always result in FASD.

Also, the discussions on whether or not there exist any effective interventions for children with FASD are framed by a scientific discourse. Although the SBU and the FAS-organization have reached different conclusions on this question, they are both building up their arguments with references to research.

In the webpage material, the existence of effective interventions are implicated as the importance of identification in order to assure 'the right kind of help and support' is repeatedly emphasized. The FAS-organization also argues for the importance of early diagnosing/identifying of FASD conditions, as this is described as favorable for the individual child's prognosis. According to the FAS-organization's campaign '1 out of 100':

Early identification has crucial consequences for the child's future development. Research has shown that if harm due to prenatal alcohol exposure is discovered before the child is 6 years old that will contribute to improved chances in the child's future adult life. (FAS-organization, 2019a)

The quote above is part of a campaign directed toward professionals in child health care centers, aimed at increasing the awareness of FASD within this part of health care. Regarding aspects of modality, both the word 'crucial' and the reference to what 'research has shown' lend a high degree of certainty to the statement that early identification is of great importance to the child's future life chances. Through these formulations the health care professional is also pointed out as an important agent with responsibility to discover children with suspected FASD.

On the basis of its own evaluation of existing research in the field, the SBU-report expresses considerably more skepticism regarding evidence for FASD specific interventions being effective:

Existing research studies do not give any clear answer whether there is any specific type of support and treatment that should be offered children fulfilling the criteria of these conditions [FASD] (SBU, 2016, p.8).

To sum up, when it comes to the nature of the FASD conditions, and aspects of prevalence and causes, the SBU explicitly defines these questions as beyond the scope of their assessment. The question of causality is however difficult to ignore, which makes SBU express indirect reservations and use lengthy formulations when trying to avoid a too uncritical use of the term FASD. As has been shown above, the SBU and the FAS-organization also communicate different perspectives on whether there is scientific support for interventions aimed specifically at FASD being effective, and this question is ascribed importance for whether diagnosing/identifying FASD conditions is motivated or not.

### ***The pragmatic discourse. What's the use of diagnosing/identifying?***

Practical aspects of diagnosing/identifying FASD are discussed in both materials. At these times, a *pragmatic discourse* is drawn upon, and the discussions focus to a high degree on the question of whether diagnosing/identifying is useful or not.

The importance of being able to explain difficulties and problems of the individual child is emphasized in both materials analyzed. This is described important both to make the child understand him- or herself in a better way, and to parents and family, who may be confronted with questions or put into challenging situations as a consequence of the child's difficulties.

The existence of a diagnosis, or a clear description of the condition, can make it easier to remain constructive in those situations that occur, when you know that the child is not able to deal with the situation in any better way than he or she does (SBU, 2016, p.103).

In the quote above, the use of diagnosing/identifying is thus motivated by its function, as it is supposed to have

positive effects on relations within the child's family. The SBU also mentions that a diagnosis can facilitate contact with other children and families in the same situation, for example via patient organizations.

Also on the webpage of the FAS-organization, the value for family and relatives of identifying FASD in children is repeatedly emphasized, particularly for foster- and adoptive parents. In information material directed to adoptive parents the importance of having an explanation of the child's difficulties is expressed with high modality:

It is important to be able to answer questions about the cause of the difficulties, both from people nearby and from the child in question (FAS-organization, 2019d).

Both the SBU and the FAS-organization thus describe the term/diagnosis as 'useful' in the sense that it facilitates the everyday life of families, both when it comes to answering questions about the child's difficulties and when making contacts with other families in the same situation.

SBU also takes quite a pragmatic stance when emphasizing that one advantage with starting to use FASD diagnoses is that this could affect political decisions of allocating resources, and also writes that the establishing of FASD diagnoses could be:

... a strong signal, to both health care and society in general, that here is a problem that has to be dealt with (SBU, 2016, p.102).

The establishing of a diagnosis is here described in instrumental terms, as an effective way to draw attention to problems experienced by a specific group of children and their families. Regarding aspects of transitivity, health care is specifically pointed out as a central agent expected to take responsibility in this question.

In the SBU-report, there are quite extensive discussions on how the use of diagnoses can favor the allocating of resources for this group of children. The report refers to international research that has confirmed the importance of having a diagnosis in order to get access to resources within healthcare, social services and the school system. However, the SBU points out that according to existing Swedish law, it is the need of the individual child, not the diagnosis, that should determine what kind of support should be given. The SBU argues that:

Doing that kind of connection, between diagnosis and access to resources, is an active choice by society, or by a particular school. An alternative would be to focus on the child's individual difficulties and help needs and adjust the support interventions to that (SBU, 2016, p.103).

The SBU thus expresses skepticism towards the idea that the difficulties of the children in question have to be framed in terms of FASD in order to assure adequate help.

The view of the SBU is not shared by the FAS-organization. In their material directed to professionals in health care, school, and social services, the FAS-organization repeatedly emphasizes that identification of FASD is crucial for being able to offer the right kind of support:

Prenatal alcohol exposure can result in lifelong disabilities. With the right kind of support and help, those affected have chances to live a good life. For this being possible, it is crucial that they are identified, assessed, and diagnosed (FAS-organization, 2019e).

In the quote above, diagnosing/identifying is with a high degree of modality described as a first, and necessary, step towards getting the 'right' sort of help and support. It is thus indirectly implied that there are effective support interventions aimed specifically at difficulties related to FASD conditions, and that only treating the difficulties in themselves is insufficient.

In the conclusions of the SBU report, doubts are expressed when it comes to the quality of existing descriptions of FASD conditions:

With the exception of the FAS diagnosis, the descriptions of the conditions within FASD are still in the stage of research and the consequences of using them in clinical practice are not clear (SBU, 2016, p.8).

Here the pragmatic discourse is clearly intertwined with the scientific discourse, as the practical consequences of diagnosing/identifying are deemed unpredictable with reference to current knowledge.

The SBU report also refers to critique formulated against the FASD diagnoses for being of limited use for identifying any specific set of symptoms. As the variation in symptoms is broad, the SBU argues that the customary connection between diagnosis and specified interventions gets lost. SBU underlines that FASD diagnoses do not seem to give any additional guidance for what interventions could be considered appropriate, more than the information already gained by identifying an individual's specific difficulties. Later on in the discussion it is stated that:

Considering the confusion and overlap between existing FASD conditions and their varying expressions, it is currently not clear whether more diagnoses (additional to FAS) within the area of FASD would be of any use (SBU, 2016, p. 119).

Taken together, the SBU emphasizes the potential usefulness of FASD diagnoses as a way to draw attention to fetal harm due to alcohol exposure and to favor the allocation of resources to the children in question. Regarding the usefulness of the diagnoses on the individual level, however, the SBU and the FAS-organization display diverging perspectives. While the FAS-organization argues that the difficulties of the individual child must be framed as FASD in order to guarantee the right kind of support and help, the SBU argues that the children in question can have their individual needs met anyway and that the help and support given do not have to be FASD specific. SBU also strongly questions the practical usefulness of diagnosing/identifying children with guidance from current descriptions of FASD conditions, as they are considered to be too broad and unspecific.

### ***The ethical discourse. Are there harmful consequences of diagnosing/identifying?***

The ethical discourse is mainly drawn on when aspects such as stigma and the risk of misdiagnosing are brought to the fore, and even if the ethical discourse is primarily structuring



these discussions, the scientific discourse is at times present as well.

A couple of times, the discussions focus on stigma. In these cases, the risk that the biological mother should experience guilt connected to the diagnosis is held forward. With reference to the limited evidence for causality between alcohol exposure and FASD, the SBU writes:

In practice, this can lead to the biological mother being blamed for causing the child's disabilities through alcohol consumption during pregnancy, even though there may be no evidence to substantiate these allegations (SBU, 2016, p.106).

The ethical discourse is thus, in this case, clearly interacting with the scientific discourse as the potential stigma effect is, with reference to the weak evidence, presented as more problematic than it would otherwise be.

This aspect is not problematized to the same extent by the FAS-organization. They underline several times in their information material directed at professionals that assessment and diagnosing of a child can contribute to feelings of guilt and shame for the biological mother. In the excerpt below, taken from an information text directed at professionals within social services, this is however presented as inevitable:

Sometimes professionals within social services have knowledge that a child has been prenatally exposed to alcohol, but as there may not be any diagnosis, the problem can be difficult to speak openly about. For the child's sake, it is however very important not to avoid to confront biological parents. A parent who has caused her child harm has a heavy burden to bear, and may be in need of support to handle feelings of guilt and shame. (FAS-organization, 2019b).

Speaking about FASD with biological parents is here presented as a challenge to the social worker, and through the word 'confront' the act is also described as quite offensive. The argument for doing this anyway is 'for the child's sake.' Confronting biological parents with suspicions of FASD is thus presented as a way to prioritize the child's perspective, even if this makes the mother feeling stigmatized. The arguments here clearly draw on an ethical discourse, and paying attention to transitivity it is clear how the social worker is positioned as an important agent, responsible for acting in line with the principle of the best interest of the child.

The SBU also expresses worries from an ethical perspective that for example ADHD and intellectual disabilities could be misdiagnosed into FASD conditions:

... there is a risk of circular reasoning. If the child has symptoms of any of the FASD conditions and there is knowledge about prenatal alcohol exposure, the conclusion can be that the symptoms are caused by alcohol, even though other causes cannot be excluded (SBU, 2016, p.117).

Finally, the ethical discourse is also drawn upon when SBU problematizes the consequences if children with FASD conditions should get favored in terms of resources. SBU discusses the term 'potential crowding out effect,' which here refers to how the group of children qualifying for a FASD diagnosis could be favored at the expense of those children who suffer from the same type of difficulties but do not fulfill diagnostic criteria:

One can even envisage a situation where children with a diagnosis are prioritized over children with more extensive needs but without diagnosis (SBU, 2016, p. 107).

The FASD diagnoses are in the quote above described as having potential to be a little too useful, in the meaning effective, when it comes to allocating resources to children with FASD conditions. Here, a structuring ethical principle for SBU's reasoning is that resources within health care, social services and the school system are limited, and therefore must be allocated in a justifiable way.

Taken together, the aspect of stigma is present in both materials but handled in two different ways. In the SBU report it is problematized with reference to the lack of evidence surrounding causality; the SBU expresses fear that mothers will be blamed for causing their children's disabilities through drinking during pregnancy, when this may not have been the primary cause. The FAS-organization does not problematize this deficiency of evidence, and the harm is with a high level of modality described as 'caused' by the mother's alcohol consumption. The potential stigmatizing effects on mothers of children with FASD are recognized also by the FAS-organization, but defined as being outweighed by the positive consequences for the child of speaking 'openly' about FASD. In this context, the social worker is presented as an important agent in the process of identifying children with suspected FASD. Finally, the SBU also draws on an ethical discourse when emphasizing the problematic aspects of how the FASD diagnoses could lead up to children qualifying for these diagnoses getting favored at the expense of other children with more extensive needs.

## Discussion

According to the sociological perspective on diagnoses (Jutel, 2009), important main functions of a diagnosis is to organize illness in a way that identifies treatment options, predicts outcomes, and provides explanations. As shown in this study, there are disagreements between the SBU and the FAS-organization on the FASD diagnoses' potential regarding all these three aspects. Above all, there are different views on the importance of framing the difficulties of prenatally alcohol exposed children in terms of FASD in order to guarantee adequate support. The view of the SBU, that it could be preferable to focus on, and treat, separate difficulties instead of taking the diagnosing/identification of the FASD conditions as a starting point, is not shared by the FAS-organization. Instead, they consider identification of FASD as crucial in order to assure the individual child the right kind of help and support. The SBU also expresses strong skepticism regarding the practical usefulness of identifying/diagnosing children with the help of existing descriptions of FASD conditions. These are deemed to be too broad and diffuse to give specific information about an individual child.

As emphasized by scholars studying the heightened awareness of fetal harm due to alcohol during the last decades, it is not always new knowledge per se that has motivated the attention drawn to FAS and FASD. Contextual factors, such as a changing view on the relation between the

pregnant woman and the fetus, and claims-making by medical experts have been pointed out as important (Armstrong, 2003), and also the impact of FASD interest organizations has been emphasized (Lowe et al., 2010). The present study also shows that references to science are central, but not entirely decisive, for how the discussions on whether or not to diagnose/identify FASD are shaped.

The analysis identified three discourses regarding the question of whether FASD should be diagnosed/identified or not: a scientific, a pragmatic, and an ethical. In this material the scientific discourse can be said to take a special position as it was often present also when other discourses were drawn upon. The dominating role of a scientific discourse is, with respect to the scientific mission of the SBU and the importance for the FAS-organization to profile itself as a serious actor in the field, not surprising. However, the scientific discourse is both acknowledged and neglected when the pragmatic and ethical discourses are at work. For example, when SBU discusses the risk of stigma, mainly drawing on the ethical discourse, they also emphasize that there is scientific uncertainty concerning the question of causality between alcohol exposure and FASD. The ethical and scientific discourses thus work together in a way that presents the risk of stigma of FASD mothers as more problematic than would it be if there were scientific certainty regarding the question of causality. On other occasions, the scientific uncertainty is left unproblematized. For example, both the FAS-organization and the SBU clearly draw on a pragmatic discourse when they describe the existence of a diagnosis as a relief for the child and its family. At the same time, when discussing clinical use, the status of scientific knowledge of FASD is repeatedly referred to and the descriptions of the FASD conditions are deemed too scientifically underdeveloped to be useful. As shown, the discourses drawn on to discuss FASD are also framed by structural factors. For example, the legislation on the rights of children to have their special needs met is referred to by SBU, and the authority also emphasizes that societal resources possible to allocate to children with special needs are limited and therefore necessary to distribute in a fair and equal way. There are also broader discourses on the social practice level, such as the principle of the child's best which is drawn upon when the FAS-organization presents the act of social workers confronting biological mothers with suspicions of their children having FASD as being in the best interest of the child.

The pragmatic and ethical discourses are both drawn on when the practical advantages of explaining the child's difficulties in terms of FASD are emphasized. One of these advantages is indirectly described to be the possibility to avoid stigma. The view that biological explanations should be less stigmatizing than psychosocial ones when it comes to mental health and behavioral problems of children is however not undisputed. For example, Lebowitz et al. (2016) showed that laypeople given biological explanations of ADHD tended to see the symptoms of ADHD as less treatable than what those given a psychosocial explanation did. At the same time, the biological explanation seemed to decrease blame against the child and its parents. The authors thus described biological

explanations of ADHD as a 'double-edged sword' (p. 248) in how it affected stigmatizing attitudes.

However, it is not possible to totally equate the situation of families with children with ADHD to those with FASD conditions when it comes to stigma. An important dimension added in the case of FASD is, needless to say, the fact that the diagnostic term in itself implies that the child's difficulties are caused by the birth mother's drinking during pregnancy. As a biological explanation could theoretically decrease blame and stigma of parents of children with ADHD symptoms, the situation is in the case of FASD thus reversed, at least regarding the birth mother's situation. An elevated risk of stigmatization in the case of FASD has also been confirmed empirically, for example in a study by Corrigan et al. (2017), where mothers of children with FASD were shown to be stigmatized to a higher degree than women with serious mental illnesses, women with substance use problems and women with jail experiences. Also stigmatization of children with FASD has been researched, and one study have showed that stereotypes of these children include a view of them as brain disordered, violent and immature (Corrigan et al., 2019).

Taken together, there is still no consensus regarding the usefulness of diagnosing/identifying FASD in Sweden. As future research will probably add new knowledge, and maybe bring clarity into the question of causality between prenatal alcohol exposure and FASD conditions as well as the question of effectiveness of FASD specific interventions, the discussions can be expected to continue. However, as underlined by Jutel (2009), diagnoses are negotiated and agreed upon in processes where different perspectives and interests are articulated. And, as shown in this study, the current state of scientific knowledge can be both invoked and disregarded when arguments are drawing on for example logics of ethics or pragmatism, or when aspects such as economical societal resources or the principle of the best interest of the child are taken into consideration. Lately, voices have also been raised, questioning established classification systems of psychiatric diagnoses in general. For example, the British Psychological Society have criticized these systems for being reductionist in viewing behavioral and emotional problems from a purely biological perspective, and instead argues for a more contextual approach to psychiatric problems, that also takes social, cultural and material aspects into consideration (Johnstone & Boyle, 2018). The future will show whether this perspective will gain ground also in the Swedish context, and if this is the case, how it will affect the interaction between currently existing discourses on FASD.

As emphasized by Fairclough (1992) aspects of production of texts, but also of consumption, are important to consider in order to make an exhaustive analysis of the relationship between discourse and social context. In this study the aspect of consumption has been left out. A suggestion for future research is to study how text materials on FASD are interpreted and reflected upon by professionals within school, health care and social services, persons who themselves have FASD related difficulties and their relatives, and decision makers within authorities and politics.

## Disclosure statement

The author reports no conflict of interest.

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