



Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Spectrum Disorders (FASD) – conditions and interventions

A systematic review and assessment of the social, medical, economic and ethical aspects

Executive summary

Objectives

The main objective of this report is to investigate whether being identified as having a condition related to fetal alcohol spectrum disorders (FASD) improves the health and social situation for the individual, or for those closest to him/her. The question was divided into two main parts:

1. How do the different FASD-related conditions impact the child, his/her relatives, and society?
2. What are the social, medical, economic and ethical effects of interventions for children with FASD-related conditions?

The association between alcohol intake and the different FASD-related conditions was not addressed. The preventive measures were also not considered.

Conclusions

FASD is a controversial term referring to several conditions, characterized by a spectrum of symptoms ranging from physical birth defects to neurodevelopmental disorders, which may be caused by the expectant mother consuming alcohol during pregnancy. FASD is not an accepted medical diagnosis in Sweden. However, fetal alcohol syndrome (FAS), which is one of several conditions classified as FASD, is a valid medical diagnosis. FAS is characterized by a complex combination of physical, psychological and cognitive anomalies.

- ▶ With the exception of FAS, definitions of the FASD-related conditions are still developed through research, and the consequences of applying them in practice for health and social services are not clear. The best course of action is therefore to provide help and support based on the specific needs of the individual and his/her family. It is also important to follow the development of interventions for other

disorders with overlapping symptoms, e.g., ADHD, autism or intellectual disability.

- ▶ Individuals with symptoms consistent with FASD, and their parents, would like professionals within the healthcare, social services and education systems to have more knowledge about FASD and offer more understanding and support.
- ▶ Research is needed that explores whether identifying an FASD-related condition benefits the individual, as is an analysis of the potential risks and costs. Existing studies provide no guidance in selecting the specific forms of interventions that should be offered to children with FASD-related conditions.

What this assessment adds

This systematic review presents the current scientific evidence regarding the prevalence of disabilities in individuals with FASD-related conditions. It also provides a summary of these individuals' experiences of living with FASD and summarizes the evidence regarding the effects of interventions.

Background

FAS is characterized by a complex set of physical traits, including growth deficiency and specific facial features, as well as evidence of central nervous system dysfunction. Partial fetal alcohol syndrome (pFAS) is an FASD-related condition that is applied to individuals who exhibit most of the symptoms consistent with FAS, but who do not meet all of the criteria for a full FAS diagnosis. Alcohol-Related Birth Defects (ARBD) is a term used to describe individuals with physical defects, but not the behavioural and cognitive impairments typically associated with FAS. A third FASD-related condition, Alcohol-Related Neurodevelopmental Disorder (ARND), describes individuals who exhibit the cognitive and behavioural

impairments characteristic of FAS, but not the associated physical traits.

This SBU assessment focuses on individuals who meet the criteria for any of the FASD-related conditions. SBU has taken no position regarding whether the disabilities assessed are caused by exposure to alcohol, or whether there are any other contributing factors.

It is not clear how many people meet the criteria for the various FASD-related conditions in Sweden. According to The Swedish National Patient Register, about ten children born in Sweden are diagnosed with FAS annually. What percentage of actual cases this represents is unclear. There is also a group of adoptive and immigrant children who have FAS. In Sweden, most children with FAS are raised by foster or adoptive parents.

Methods

SBU was commissioned by the Swedish Government (Reg. no. STY2015/59) to assess FASD. The project was conducted in collaboration with The National Board of Health and Welfare and The Public Health Agency of Sweden. The assessment systematically reviews the scientific literature on the effectiveness and cost-effectiveness of interventions aimed at individuals with FASD and their parents; the FASD-related social costs; the prevalence of disabilities and the social situation of individuals with FASD; as well as the experiences of individuals with FASD and their families regarding the condition and interventions. The certainty of the evidence was assessed using GRADE or CERQual. As a complement to the systematic literature review on the prevalence of disabilities and the social situation, we have conducted a registry study on children in Sweden who are diagnosed with FAS.

Collaboration with a non-profit organisation for individuals with FASD and their relatives (FAS föreningen) was established to highlight their perspective.

Socioeconomic and ethical aspects are discussed based on the published literature, as well as on discussions with experts from both the FASD project group and external reference groups.

Main results

- **Described experiences of those living with FASD.** Individuals with symptoms consistent with FASD feel their lives are limited by a number of cognitive/physical disabilities as well as social limitations. Parents of children with FASD feel stressed and socially isolated; they worry about their child's future. In addition, they also feel

that the professionals they meet are insufficiently informed about FASD and they experience lack of understanding for their situation. These parents would like to encounter better-informed and more understanding healthcare, school, and social services personnel.

- **Value of identifying FASD-related conditions as a basis for assessing needs and planning care.** With the exception of the medical diagnosis FAS, there is insufficient scientific evidence to determine the benefits or risks associated with identifying any of the other FASD-related conditions. There are too few high-quality studies examining the prevalence of disabilities in these populations, or exploring whether there are specific interventions that improve their situation. Parents of children with symptoms consistent with an FASD-related condition report having mixed feelings, including both grief and relief, when it is concluded that their children have an FASD-related condition.
- **Effects of interventions.** It is not possible to determine the benefits or risks of interventions aimed specifically at children with FAS, or any of the other FASD-related conditions, due to the lack of high-quality studies. Research on potentially relevant interventions has been done for other conditions with overlapping symptoms, such as ADHD, but such studies have focused only rarely on individuals with FASD. Studies of isolated interventions suggest it is possible to help these children with, for example, their schoolwork, although the evidence is weak and the direct impact on their social or overall well-being has not been assessed.
- **Further research needs.** More studies focusing on individuals who are representative of the various FASD-related conditions are needed to determine the extent of the physical, psychological and social difficulties of each group; more research highlighting the perspectives of the biological parents is also needed. Such studies could provide a basis for future research into how interventions influence both the long- and short-term experiences, social situations, and well-being of individuals with FASD and their relatives. Studies are also needed that explore how interventions developed to address developmental and behavioural problems in people with other diagnoses, for example ADHD, can best be adapted to individuals with FASD. For example, it may be possible to adapt existing family support interventions to children with FASD and their families.

Discussion

Children with FASD may have difficulties on many different fronts, without meeting the full criteria for any established diagnosis, e.g. ADHD, autism, or intellectual disability. It is important that these children and their families not go unnoticed; regardless of diagnosis, they need to be treated in a professional manner and provided with appropriate care and support from the healthcare and social services, as well as proper support in school.

Although we do not yet know the exact extent of the disabilities or the nature of the social situation experienced by children who meet the criteria for the various FASD-related conditions, there is some knowledge about which disabilities are characteristic of FASD. It is important to keep this information in mind when assessing the needs of each individual.

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SBU Assessment no 258, 2016

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Graphic Design: Åsa Isaksson, SBU