

How to strengthen the focus on children affected by prenatal alcohol exposure to help them lead a good life?

A Nordic report with recommendations



Nordic Welfare
Centre

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Foreword

The Nordic Welfare Centre launched its first project on alcohol and other substances in relation to pregnancy in 2019. The report [Identifying use of alcohol and other substances during pregnancy – A Nordic overview](#) was published in 2020 and focused on identifying the use of alcohol, tobacco and other substances among pregnant women across the Nordic countries. In dealing with the consequences of alcohol use during pregnancy, the report was chiefly concerned with foetal alcohol spectrum disorder (FASD).

The summing up and conclusions of the report show that the Nordic health authorities recommend abstinence from alcohol during pregnancy. There is also a need for prevalence studies on FASD to establish the actual size of the problem, which is unknown for several reasons. One of them pertains to the nature of FASD as an undiagnosed disorder. Without knowing the extent of the problem, it is difficult to get the necessary political attention and the right support for the affected population group to ensure better interventions targeted at alcohol use during pregnancy. Prenatal alcohol exposure in the Nordic countries is something of a blind spot that calls for more attention.

As the conclusions of the report raised more questions to study – especially regarding the affected population group – the Nordic Council of Ministers granted funding for a second project. This report is the outcome of that project. The primary focus of this report is the post-pregnancy period and the support and follow-up for children born with prenatal alcohol exposure, and their families.

The Nordic expert group that was appointed as a part of the first project have also had an important role in the making of this report. We would like to thank the members of this group for participating in and contributing to an initial discussion of the report's contents and focus. Special thanks are due to the two experts based at the Norwegian Regional Competence Center for children with prenatal alcohol/drug exposure (Sørlandet Hospital Arendal): Gro Løhaugen, neuropsychologist and head of the centre, and Professor Jon Skranes, child neurologist and senior consultant at the centre, for their final review of the report.

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Introduction

Alcohol is a legal and socially accepted substance in the Nordic countries, consumed in all parts of society. However, a safe level of alcohol consumption during pregnancy has not been established, and the safest option is therefore total abstinence for the duration of pregnancy. The health authorities in the Nordic countries have adopted a precautionary principle and recommend that women forgo drinking entirely during pregnancy and preferably from the time they plan to become pregnant. Any amount and type of alcohol may harm the foetus throughout the pregnancy and have lifelong consequences for the child. This message is important for all women regardless of their background and societal position (Mamluk et al., 2017; Nissinen & Frederiksen, 2020; Behnke et al., 2013).

Similarly to the Nordic health authorities, who do not recommend using alcohol during pregnancy, the World Health Organization (WHO) highlights the issue in the new version of the global alcohol action plan 2022–2030 to strengthen the implementation of the global strategy – now being drafted – to reduce the harmful use of alcohol. According to the action plan, one of the most dramatic manifestations of harm to persons other than the drinkers themselves are consequences of prenatal alcohol exposure that may result in the development of foetal alcohol spectrum disorder (FASD). The WHO also makes a point of there being no safe limit for alcohol consumption at any stage of pregnancy (WHO, 2021).

The Nordic health authorities may recommend abstinence from alcohol during pregnancy, but public attitudes on pregnant women's alcohol consumption are nevertheless an interesting phenomenon to look at. Since 2010, the so-called IQ-initiativet in Sweden has conducted an annual survey to track the attitudes to alcohol in Sweden. In 2021 the same attitudinal survey was also conducted in Denmark, Finland, and Norway. The 2021 results are based on 4,020 interviews in Sweden and on roughly 1,000 interviews in Denmark, Finland, and Norway, including participants aged 16 years and up. Among the survey questions is one regarding drinking a glass of wine or beer when pregnant. Table 1 summarises the responses to this specific question.

Table 1: Is it OK to drink a glass of wine or beer when you're pregnant?

	Wrong	Fine	Neither right nor wrong/do not know
Sweden	82%	4%	14%
Norway	84%	3%	13%
Finland	86%	5%	9%
Denmark	64%	9%	27%

(IQ-initiativet, 2022)

The table shows that over 80 percent of Swedes, Finns, and Norwegians think it is wrong to drink alcohol when you are pregnant, while 64 percent of the Danes think so. Also, 9 percent of the Danes consider it is fine to drink some wine or beer when pregnant, whereas the percentage is at 5 percent or below for the other Nordic countries.

The survey is not designed as research and the results should be interpreted with caution, but they may indicate how people think about (and possibly act in relation to) alcohol consumption during pregnancy in Sweden, Norway, Finland and Denmark. In all these countries, the percentage of people who think it is neither right nor wrong/do not know if it is okay to drink a glass of wine or beer while pregnant is higher than the percentage of those who think it is wrong. This is worrying, and the results underline that there may be a need to increase awareness among the Nordic population of the risks of pregnant women's alcohol consumption. This might help to achieve a positive change in the attitudes towards abstinence from alcohol use during pregnancy (IQ-initiativet, 2022).

The Nordic region envisions to be the most sustainable and integrated region in the world by 2030. An action plan has been drawn up, based on 12 objectives linked to the strategic priority areas: a green Nordic region, a competitive Nordic region, and a socially sustainable Nordic region. Objective 9 states that by 2024, the Nordic Council of Ministers will contribute to good, equal, and secure health and welfare for all, which is fundamental for people's ability to reach their full potential and contribute to the development of society (Nordic Council of Ministers, 2020). The vision is inspired, among other things, by the United Nations Agenda 2030 and the Sustainable Development Goals (SDGs), which the Nordic region is also very focused on achieving. Alcohol has an adverse effect on reaching 12 of the 17 overarching SDGs on Agenda 2030. In terms of child health, the key target of 3.2 seeks to end preventable deaths of newborns and children under 5 years of age. Alcohol use during pregnancy is the direct cause of foetal alcohol syndrome (FAS), but it also increases the risk of miscarriage, premature birth, and FASD. It is estimated that 25.2 percent of women in the WHO European Region consume alcohol during pregnancy. The prevalence of FAS in the WHO European Region is estimated at 3.74 per 100,000 population, which is more than twice as high as for all other WHO regions (WHO Regional Office for Europe, 2020).

Aim

There is a need to focus more on the issue of alcohol consumption during pregnancy and on its consequences, not least because an innocent population has to live with the effects of this risky behaviour. This population should have the opportunity to be identified and receive the appropriate support and services they need to live a good and healthy life.

In this report, the Nordic Welfare Centre provides recommendations to the Nordic countries on how to prioritise and strengthen the focus on children and their families affected by prenatal alcohol exposure to ensure them the best framework for a good life. More knowledge is needed about prenatal alcohol dependence and its consequences (FASD) in health care and among health professionals. With the right knowledge and skills, health professionals are better able to identify women who use alcohol during pregnancy, and they can better identify a child who may be at risk of FASD. As prenatal exposure to alcohol has lifelong consequences, we also highlight the need for and importance of individual support and follow-up for affected children, and their families. In addition to having a health-promoting effect on the target group, the recommendations can also benefit society and the economy at large.

Facts about foetal alcohol spectrum disorder (FASD)

Alcohol use during pregnancy is a significant public health issue warranting more attention. Prenatal alcohol exposure can cause lifelong disabilities to a child in varying degrees. Prenatal alcohol exposure affects not only the individual but also their family and the society. Even a small amount of alcohol at any time during the pregnancy can potentially harm the developing foetus, and heavy drinking or misuse of alcohol during pregnancy is especially harmful to foetal development.

What is FASD?

Foetal alcohol spectrum disorder (FASD) is a non-diagnostic umbrella term that refers to a broad spectrum of effects associated with prenatal exposure to alcohol. FASD includes the clinical diagnosis of foetal alcohol syndrome (FAS) and the conditions of alcohol-related birth defects (ARBD) and alcohol-related neurodevelopmental disorder (ARND). A criterion for the conditions of ARBD or ARND is a confirmed history of alcohol exposure during pregnancy.

FAS represents individuals severely affected by prenatal alcohol exposure. A diagnosis of FAS typically requires the confirmation of prenatal alcohol exposure, although the diagnosis can also be given without it. The FAS diagnosis also requires the presence of outward signs such as characteristic facial features (for example, smooth philtrum, thin upper lip, small palpebral fissures), evidence of prenatal and/or postnatal growth deficiency, and central nervous system abnormalities (for example, structural brain abnormalities such as small head size or functional impairments including cognitive deficits such as learning or memory impairments, or behavioural deficits such as attention or impulse control deficits) (Hoyme et al., 2016).

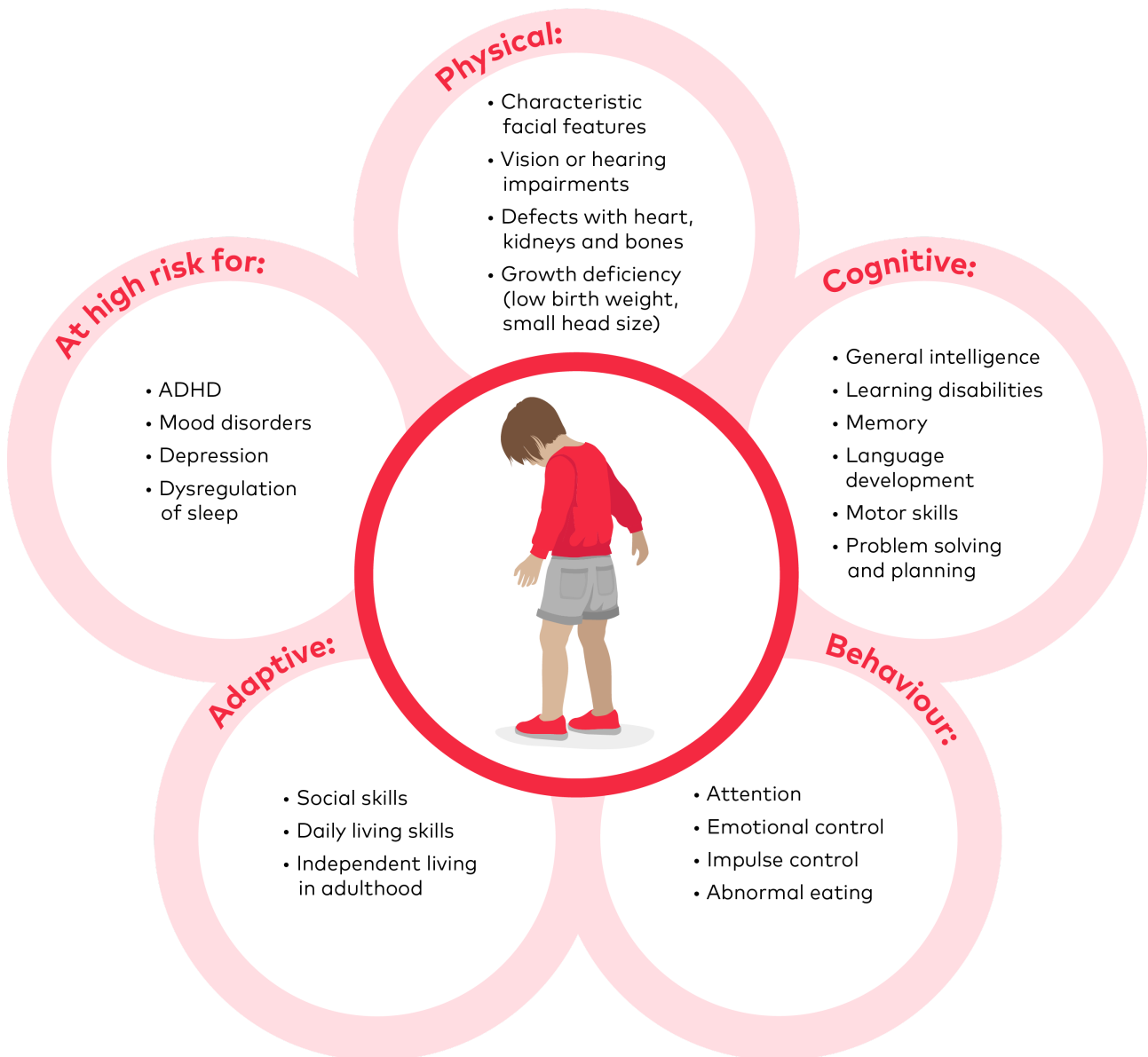
FASD is often referred to as a hidden disability, because not all individuals exposed to alcohol during pregnancy are born with FAS or present the outward signs of prenatal alcohol exposure. However, the invisible brain impairments can cause many challenges in everyday life. In addition, the typical gap between the chronological age and developmental age creates challenges, as an individual exposed to alcohol during pregnancy may not be able to perform at the expected level.

The effects of prenatal alcohol exposure are influenced by several factors including the frequency and quantity of alcohol consumed during pregnancy and the developmental timing in which alcohol exposure occurs. Thus, the effects of prenatal alcohol exposure can vary individually. Some individuals exposed to alcohol during pregnancy may show mild symptoms such as milder behavioural regulation impairments. At the other end of the spectrum are severely affected individuals with impairments in a range of developmental areas such as learning, memory, behaviour, or social interactions, or individuals with intellectual disability.

Individuals exposed to alcohol during pregnancy, especially those born to mothers who misuse alcohol, can also be at risk of other prenatal risks such as tobacco smoking, use of other substances including illicit drugs, and poor nutrition. Furthermore, early life adversities such as parental substance misuse, mental health problems, interparental conflicts, or neglect of care may endanger the childhood development of those exposed to alcohol during pregnancy (Flannigan et al., 2021).

Figure 1 illustrates the broad spectrum of difficulties and impairments that can be common among individuals with FASD and can affect an individual throughout their entire lives. Individuals with prenatal alcohol exposure can also face other challenges in life not described in figure 1, including inappropriate sexual behaviours, unemployment, trouble with the law, and drug and alcohol use problems (Rangmar, et al., 2015; Pei et al., 2018).

Figure 1: Illustration of potential difficulties and impairments commonly seen in individuals with FASD



Lack of universal diagnostic guidelines and prevalence estimates of FASD

There are no universal, globally used, diagnostic guidelines for FASD. Instead, there are various, slightly different, diagnostic guidelines for diagnosing conditions within the FASD spectrum. The diagnostic guidelines can include, for example, the 4-Digit Diagnostic Code System developed at the University of Washington or the Clinical Guidelines for Diagnosing FASD, issued by the Institute of

Medicine (IOM) (since 2015 the National Academy of Medicine in the United States). The use of diagnostic guidelines varies across the Nordic countries, with different diagnostic criteria.

Although the Nordic countries use different diagnostic guidelines, they do commonly apply the International Classification of Diseases (ICD) maintained by World Health Organization. The ICD is a diagnostic classification system for the clinical setting. With respect to FASD, the ICD classification lists a diagnostic code for FAS (Q86.0 in the 10th version) but no other FASD-specific codes are available. Other diagnostic codes within the ICD classification system can be employed to diagnose conditions the child exhibits, but there is no consensus across the Nordic countries on the codes used.

The variation in the use of diagnostic guidelines and diagnostic codes makes it difficult to establish comparable and accurate estimates of the prevalence of FASD in the Nordic countries. Attempts have been made to estimate the prevalence of FASD. In a systematic review and meta-analysis, the prevalence for FASD per 10,000 population was estimated to vary from 70/10,000 in Iceland to 360/10,000 in Denmark (Lange et al., 2017). However, the prevalence estimates have limitations, so they should be interpreted with caution.

Despite these limitations, the current prevalence estimates of FASD are likely to be underestimated: many children are not diagnosed or are misdiagnosed with other disorders. For example, in a study of adopted youth and youth in foster care, nearly 87 percent of the youth meeting the criteria for FASD had never been previously diagnosed or had been misdiagnosed (Chasnoff et al., 2015).

As shown in table 2, the prevalence estimates of FASD exceed those of another known developmental disorder such as Down syndrome.

Table 2: Prevalence (estimates) of different developmental abnormalities

	Prevalence estimates of FASD (per 10,000 population)	Prevalence estimates of FAS (per 10,000 population)	Prevalence of Down syndrome (per 10,000 live births)
Denmark	360/10,000 ¹	68.0/10,000 ²	2.9/10,000 ³
Finland	124/10,000 ¹	23.3/10,000 ²	10.1/10,000 ⁵
Iceland	70/10,000 ¹	13.1/10,000 ²	2.2/10,000 ⁵
Norway	178/10,000 ¹	33.6/10,000 ²	10.8/10,000 ⁴
Sweden	74/10,000 ¹	13.9/10,000 ²	9.8/10,000 ⁵

(¹Lange et al., 2017; ²Popova et al., 2017; ³Dansk Cytogenetisk Centralregister, n.d.; ⁴Folkehelseinstituttet, n.d.; ⁵WHO Regional Office for Europe, 2021)

NB! The data by ¹Lange et al. (2017) and ²Popova et al. (2017) should be interpreted with caution, for the data is based on small, older studies that may not be representative of the countries' situation today.

Significant costs attributable to FASD

Individuals with FASD require support from a range of services throughout life. Hence, FASD contributes to significant costs in societies. The direct costs include healthcare, child welfare services, social services, special education, and law enforcement. The indirect costs can stem from productive losses due to increased morbidity and productivity losses of caregivers of children with FASD (Greenmyer et al., 2018).

As with the prevalence estimates of FASD, there is also a lack of estimates of FASD-related costs in the Nordic countries. A Swedish study has estimated the annual costs of FAS in Sweden to be approximately 1.6 billion euros with a prevalence estimate of FAS of 0.2 percent in the Swedish population. However, the costs are likely to be higher if costs related to the whole FASD spectrum are considered (Ericson et al., 2017).

Studies from outside the Nordic region have also shown significant FASD-related costs. The results of a review analysing studies from Canada, the United States, Sweden, and New Zealand showed that the annual FASD-related costs would be approximately 23,000 US dollars per child and 24,000 US dollars per adult (Greenmyer et al., 2018). With the current prevalence estimates, direct and indirect FASD-related costs could be expected to be millions of euros every year, exceeding the costs of, for example, autism (Popova et al., 2011).

Although the estimates of FASD-related costs come mainly from countries outside the Nordic region, these studies nevertheless provide an insight into the economic burden that FASD can cause in a society.

There is no cure for FASD, but with early identification, diagnosis, continuous services, and support for individuals with FASD and their families, there is potential to improve the life of the affected and to prevent the development of adverse long-term consequences. Early and sustained efforts can reduce associated costs, and these efforts can also help to reduce the risk of future pregnancies that carry the possibility of prenatal alcohol and/or other substance exposure.

Recommendation 1: Training of healthcare professionals on FASD

There is a need to increase knowledge about prenatal alcohol use and its consequences (FASD) in healthcare and among healthcare professionals in the Nordic countries. Accurate knowledge, training, and skills help healthcare professionals to, for example, discuss the possibility of prenatal alcohol exposure and better identify a child who may be at risk of FASD.

Recommendations to the Nordic countries:

- a. Include FASD in the curricula of healthcare professionals' education and provide continuous training on FASD.
- b. Provide training for healthcare professionals on guidelines for assessment and diagnosis of conditions within the FASD spectrum and exclude other diagnoses.
- c. Provide training for healthcare professionals on ethical issues such as how to discuss the diagnosis within the FASD spectrum in a supportive and natural way to reduce stigma. This is especially important when biological parents are involved.
- d. Provide training for healthcare professionals on how to manage conditions within the FASD spectrum and co-morbidities (including making treatment plans or intervention recommendations).

Identifying and diagnosing FASD requires a trained multidisciplinary team

A single medical test that can be used to diagnose FASD does not exist. The diagnostic process is rather complex and requires a trained multidisciplinary team. Healthcare professionals, including medical professionals and psychologists, have a key role in this process. It is therefore crucial to train them to identify and spot people with FASD.

Healthcare professionals have an important role in the identification of individuals at risk of FASD, in referring them to further assessments, and in diagnosing the potential effects of prenatal exposure to alcohol. However, studies have pointed out that healthcare professionals lack knowledge and experience to identify and diagnose conditions within the FASD spectrum (Payne et al., 2005; Howlett et al., 2019; Elliott et al., 2006). The studies also show that only a minority of healthcare professionals are trained in the follow-up of patients with FASD. Education and training of healthcare professionals is therefore important.

The training of healthcare professionals is also important in order for them to be able to understand that many risk factors may be responsible for the individual's clinical picture. Crucially, healthcare professionals need to be able to differentiate FASD from other disorders. Often, the challenge of diagnosing conditions within the FASD spectrum and differentiating conditions from other disabilities lies in the inability to confirm prenatal exposure to alcohol. Without information on this exposure, it is hard to differentiate FASD from other disorders that manifest in ways similar to FASD. Healthcare

professionals can and should be trained to have a conversation with mothers (and their partners) about the possibility of prenatal alcohol exposure. It can also be challenging to identify individuals who do not show the outward signs of prenatal alcohol exposure yet exhibit cognitive and behavioural deficits commonly seen in individuals with FASD (Chudley et al., 2007).

Diagnosing conditions within the FASD spectrum is a complex medical diagnostic process. Because of the complexity and broad array of outcomes observed in prenatally alcohol-exposed individuals, the accurate and comprehensive assessment of physical and neurodevelopmental effects requires a multidisciplinary clinical team. The team can consist of, for example, paediatricians, other relevant physicians, dysmorphologists, psychologists, and speech-language pathologists with complementary experience, qualifications, and skills needed for the diagnosing process (Hoyme, et al., 2016). The healthcare professionals involved in the diagnostic process need training to use the diagnostic guidelines accurately. The multidisciplinary team also has an important role in sharing the assessment results and making intervention or treatment recommendations to the affected individuals and their families. In addition, this is not just an educational and a training issue, but also a question of capacity. The limited capacity and expertise, and the need to involve a multidisciplinary team in the process of diagnosing conditions within FASD, can lead to only a fraction of those affected to be assessed and diagnosed (Chudley et al., 2005).

Research has shown that healthcare professionals may understand the benefits of the diagnosis within the FASD spectrum but can be concerned about the stigma attached to a FASD diagnosis. This can affect their willingness to engage in FASD-related work. Training for healthcare professionals is therefore necessary: it can increase their knowledge and understanding of FASD. Additionally, training can provide a catalyst to change attitudes towards drinking alcohol during pregnancy and FASD, and reduce the stigma attached to the topic. Training can also prepare healthcare professionals to discuss the diagnosis with the affected individuals and their families. Moreover, a diagnosis within the FASD spectrum concerns not only the affected individual but also the biological mother. Training is key to handling the ethical issues related to FASD (Bagley & Badry, 2019; Elliott et al., 2006; Payne et al., 2005).

Recommendation 2: Support and services for individuals with FASD

Prenatal exposure to alcohol has lifelong consequences. Support and services should be tailored individually, as should the follow-up of affected children and their families to give them the best framework for a good life.

Recommendations to the Nordic countries:

- a. Provide a child- and family-centred health and social care system that offers multidisciplinary and cross-sectorial support and services for individuals with FASD and their families.
- b. Provide an intervention or treatment plan for individuals with FASD and their families based on their individual needs. The individualised support should also take into consideration the caregiving environment.
- c. Provide parental training to help parents better understand their child's areas of challenges and respond to their child's needs to improve everyday life.
- d. Provide long-term follow-up. The need for support and services can continue into adulthood for many children and adolescents with FASD.

Early treatment and interventions for individuals with FASD

The assessment of symptoms of prenatal alcohol exposure and diagnosis is not the endpoint for the individuals with FASD and their family. These are rather a part of a continuum of care that aims to better understand the individual's strengths and areas of challenges and needs of support. The diagnosis can help to find appropriate services and support options for the individual with FASD and for the family. Given the spectrum of disorders associated with prenatal alcohol exposure, as well as the age and maturity of those affected, services to affected individuals and their families have to be individually adapted as each case involves individual needs.

Individuals with FASD may need support and services throughout life. There is no one intervention or treatment model that fits all individuals exposed to alcohol during pregnancy. The treatment for individuals with FASD can include medical treatment, therapies targeting the areas in which the individual with FASD is challenged, and parenting training following individual needs. Interventions that maximise the protective factors such as early identification and diagnosis and early individualised support and follow-up and reduce the number of risk factors such as an unsafe and unstable childhood caregiving environment are likely to bring positive outcomes and prevent long-term consequences.

Children exposed to alcohol during pregnancy may require support and follow-up after birth already. They may need intensive care due to premature birth, withdrawal symptoms, irritability or feeding problems. Frequent follow-ups with different healthcare professionals may also be needed during the early years or later in life to treat other comorbid conditions. Later in childhood and adolescence, individuals with FASD can benefit from therapies including speech-language therapy, occupational

therapy, physical therapy, and neuropsychological rehabilitation. These therapies can target domains where the exposed individuals have impairments, including verbal and social communication, motor skills, attention, self-regulation, as well as adaptive functioning. In addition, individuals with FASD may also benefit from services and therapies provided by psychologists and psychotherapists, targeting, for example, co-occurring mental health issues and challenges with social skills (Petrenko & Alto, 2017). Specific medical treatments for FASD do not exist, but some medications can be used to treat symptoms such as hyperactivity, poor impulse control, anxiety, sleep problems, or mood disorders (Petrenko & Alto, 2017).

It is likely that individuals with FASD are in contact with multiple services and systems throughout life. Good communication between healthcare, educational, social workers, and other professionals who are in contact with the child and the family can be a key to understanding the child's strengths and challenges holistically, and tailoring individualised support and services for the child.

A healthy caregiving environment is important for a child's health and development

A safe, responsive, and nurturing caregiving environment has a significant influence on children's health and development. Children born to mothers with alcohol misuse during pregnancy can be exposed to double jeopardy. Not only do they have an increased risk of adverse birth outcomes and subsequent cognitive and behavioural impairments, but they can also be vulnerable to multiple risk factors in the caregiving environment that can negatively influence their development. These risk factors can include parental alcohol and other substance misuse, mental health problems, low socioeconomic status, interparental conflicts, child abuse, and neglect of care. For the child welfare services these risk factors can also be indications of an unhealthy caregiving environment. In the most severe cases, the children can be placed in out-of-home care during their early years (Flannigan et al., 2021; Staton-Tindall et al., 2013).

Consequently, these children and their families need intensive support across a range of services targeting child health and development, safety, and stability of the caregiving environment as well as parental psychosocial conditions. The interventions can also target parenting areas and caregiver-child interaction, which is especially important among families with alcohol misuse (THL, 2021).

Summing up and conclusions

Alcohol use during pregnancy and FASD are significant public health issues warranting more attention and action. With this report we emphasise the need to raise awareness of alcohol use during pregnancy and of FASD, prioritise screening and the diagnosing of FASD, as well as the prevention of FASD in societies. Healthcare professionals including medical professionals are the catalysts for these actions, which can positively influence the individual's life and wellbeing and help them reach their full potential of being active members of society, which also benefits the society itself.

From an individual's perspective, the diagnostic assessment and diagnosis within the FASD spectrum can positively influence the wellbeing of the exposed individual and their family. The diagnosis may provide explanations and preparedness for the potential difficulties an exposed individual may encounter in everyday life and assist in acquiring help and support at an early stage. It can help to find appropriate services and support options for the individual with FASD and for the family. Furthermore, it can also help to communicate within and outside the family and find peer support or others experiencing similar difficulties. An early diagnosis and the right support and follow-up can prevent an affected individual from experiencing other problems later in life such as educational challenges, mental health issues, or challenges to establish adult independence.

Delayed diagnosis or misclassification of outcomes can lead to unrealistic developmental expectations, inappropriate care, increased risk of behavioural and social problems later in life, missed opportunities for prevention, and inaccurate estimates of the prevalence of FASD. Together, these can contribute to economic costs to societies and hinder the allocation of resources and services to the exposed population (Chudley et al., 2005; Helgesson et al., 2018).

From a societal perspective, there are many benefits and advantages to making appropriate interventions and improvements in FASD-related work. Among other things, it can help to reduce the related costs associated with FASD. Appropriate measures can also benefit FASD-related research and aim to provide better prevalence estimates. More accurate prevalence estimates can help to understand the true extent of the problem, provide a better basis for understanding the costs of FASD, and provide a basis for allocating resources to FASD-related work. In addition, these measures are also essential for the development of evidence-based interventions and other practices related to FASD.

The Nordic countries need to focus policy attention and priority on the public health problem of alcohol use during pregnancy and its consequences for the child in particular. This innocent population group has to live with the consequences of another person's risky behaviour for the rest of their lives. They deserve to be seen, identified, and diagnosed (if necessary) to receive the appropriate support and services they need in order to live a healthy life and reach their full potential, which is also beneficial for society.

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A Nordic report with recommendations

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