

# Fetal Alcohol Spectrum Disorders

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Report from expert meeting  
Helsinki 10-11 October 2019



Nordic Welfare  
Centre

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# Introduction

Alcohol is the most harmful of all substances, when it comes to the risks for the baby. Maternal alcohol consumption during pregnancy can have devastating effects on the developing fetus at any stage during the pregnancy.

Most women reduce alcohol consumption or stop using alcohol when they become pregnant. However, four out of ten pregnancies are unplanned, and the consumption of alcohol (and other substances) has been increasing among women in childbearing age, imposing a risk of exposure to the fetus before a woman knows she is pregnant.

Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term and describes the range of effects that may occur due to prenatal alcohol exposure, including prenatal and postnatal growth deficits and central nervous system abnormalities among others.

This report focuses on the expert meeting on FASD held in October 2019 as a part of Nordic Welfare Centre's project Use of alcohol and other substances during pregnancy – in a Nordic perspective.

The report gives an insight to what was on the agenda for the expert meeting, how it was structured, which occupational and interest groups participated, what was discussed, the purpose, expectations, and highlights of the meeting, and what the outcomes for further Nordic collaboration are.

The report is mainly targeted at the participants of the expert meeting as a summary of the meeting and its outcomes. However, everyone who has an interest in the field of FASD may also find it interesting.

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# About the expert meeting

On the 10-11 October 2019, the Nordic Welfare Centre hosted an expert meeting on FASD in Helsinki, Finland, as a part of the project Use of alcohol and other substances during pregnancy – in a Nordic perspective. Experts from across the Nordic region were invited to participate in the meeting, and present were 22 participants representing Norway, Sweden, Finland, Denmark and Iceland. To get a broad perspective on the topic of FASD, experts from different occupational and interest groups were invited covering the fields of research, clinical and healthcare work, the health authorities, Fetal Alcohol Syndrome (FAS) associations etc.

The main purpose of the expert meeting was to get an insight of the field of FASD, and the work done in and across the Nordic countries. The purpose was also to identify problem areas and find solutions within the field of FASD, and to come up with a plan for the continuous work across the Nordic region. In addition, the purpose of the expert meeting was also to facilitate Nordic networking and Nordic collaboration.

# Day one: Identifying problem areas

## Programme of Thursday 10 October

- 11.00**      **Meet and registration at Folkhälsan**  
Address: Topeliuksenkatu 20, 00250 Helsinki
- 12.00**      **Welcome and introductions**  
Welcome words by Nina Rehn-Mendoza, Director of Public Health, Nordic Welfare Centre
- 12.45**      **Presenting Nordic Welfare Centre's project *Use of alcohol and other substances during pregnancy – in a Nordic perspective***
- 13.15**      **Group work**  
What is working and what needs to improve in the FASD field in the Nordic countries?
- 14.30**      **Coffee / Tea break**
- 15.00**      **FASD – a blind spot**  
Keynote speaker: Ilona Autti-Rämö, General Secretary, Council of choices in health care, Ministry of Social Affairs and Health, Finland
- 16.00**      **Wrap up**  
- Plenary discussion of the group work  
- Wrap up of day one

## Expectations for the expert meeting

The expert meeting on day one started with introductions of each participant and the sharing of expectations for the expert meeting.

The expectations for the expert meeting were:

- Mutual attempts to collect and register data and measure prevalence (of alcohol use among pregnant women and FASD)
- Establish an FASD association in all Nordic countries
- Collaboration, networking, and new contacts
- Support from the Nordic Welfare Centre to focus on FASD
- Research collaboration
- Different programs from the Nordic countries on preventing substance abuse among pregnant women
- Screening alcohol/substance use among pregnant women in the Nordic countries
- Diagnostic criteria for FASD
- How to support people with FASD
- New ideas in general

## Use of alcohol and other substances during pregnancy - in a Nordic perspective

The day continued with a presentation of the Nordic Welfare Centre, and the project Use of alcohol and other substances during pregnancy - in a Nordic perspective.

The project was initiated in March 2019 on suggestion from the Norwegian Directorate of Health. The project focuses on smoking, alcohol and other substance use during pregnancy and the harms to the fetus caused by maternal substance use during pregnancy.

The target group for the project is researchers, healthcare workers and other relevant practitioners, officials, non-governmental organizations (NGOs), and service providers who work in the field.

Project deliveries during 2019 are a report on the use of alcohol during pregnancy in a Nordic perspective and an expert meeting on

Fetal Alcohol Spectrum Disorders (FASD), which is presented in this report.

## Group work

The day continued with group work. The participants were divided into four groups mixed with members from different occupations and from across the Nordic countries. The task was to identify what is not working in the FASD field, and what is working well. The participants had a few minutes to identify the areas by themselves before discussing the topic as a group. As a group, they had to choose three problem areas that they think need to be improved in the FASD field. The problem areas identified (see table 1) were presented for all participants at the later plenary discussion of the group work.

**Table 1: The problem areas identified in the group work**

Group	Problem areas identified
1	<ol style="list-style-type: none"><li>1. Prevalence and diagnostic facilities of FASD</li><li>2. Identification of alcohol users in early pregnancy</li><li>3. Professionals meeting women in early pregnancy need to have more knowledge on the effects of low alcohol consumption, FASD, and how to address this</li></ol>
2	<ol style="list-style-type: none"><li>1. Need for more knowledge among public and professionals</li><li>2. The need for systematic data collecting</li><li>3. Need for diagnosis and support for affected children and young adults</li></ol>
3	<ol style="list-style-type: none"><li>1. Nordic collaboration in research</li><li>2. Follow-up of mothers and their children with FAS and FASD</li><li>3. A common Nordic platform for dissemination of guideline, research etc.</li></ol>

	4. (Diagnostics)
4	<ol style="list-style-type: none"> <li>1. Information to fertile age/pregnant women and health care professionals, including education in high school (using e.g. social bloggers)</li> <li>2. Diagnosing + screening + follow-up program (prenatally drug-exposed)</li> <li>3. How to help the child and the families: intervention - does it work?</li> </ol>

## Keynote speaker, Ilona Autti-Rämö, Finland

After the group work, the keynote speaker Ilona Autti-Rämö from Finland gave a presentation on "FASD - a blind spot". In the presentation, Autti-Rämö gave a brief history of FASD in Finland and talked about the current trends in the field of FASD, and in research. Autti-Rämö discussed what has been done within primary prevention, what has changed regarding secondary prevention and what is lacking within tertiary prevention related to the FASD field. Autti-Rämö also talked about what needs to be changed in the field of FASD and highlighted attitudes, inpatient and outpatient services for substance misusing pregnant women, and the willingness to diagnose FASD. Autti-Rämö highlighted the need of prevalence studies of FASD, which are needed also for political purposes.



# Day two: Finding solutions

## Programme of Friday 11 October

- 9.00**      **Agenda of the day**
- 9.15**      **FASD – clinics and research in Norway. Experiences from the Regional Competence Center for children with prenatal alcohol / drug exposure, Sørlandet Hospital, Arendal**  
Keynote speaker: Jon Skranes, Senior paediatrician / Professor dr. med., Sørlandet Hospital, Arendal, Norway
- 10.15**      **Group work**  
Discussion of solutions for the problem areas discovered on day one
- 11.30**      **Lunch**
- 12.15**      **Group work continued followed by a plenary discussion of the group work**
- 14.00**      **Coffee / Tea break**
- 14.30**      **Wrap up**  
- Wrap up of the meeting  
- What could be the next steps within the FASD field in the Nordic context
- 15.30**      **End of expert meeting**

## Keynote speaker, Jon Skranes, Norway

Day two started with a presentation by keynote speaker Jon Skranes from Norway. In the presentation titled FASD in Norway - Experiences from the Regional Competence Center for children with prenatal alcohol/drug exposure, Skranes discussed the prevalence estimates of alcohol use among pregnant women in Norway and FASD. Skranes presented the work done at the Regional Competence Center for children with prenatal alcohol/drug exposure in Arendal, Norway and how affected children (0-18 years old) are diagnosed with FASD: what is the procedure at the center and what happens after the assessment at the center. Skranes also addressed the challenges in diagnosing FASD, the diagnostic criteria used at the center, and when not to diagnose FASD. In the presentation, Skranes also talked about the comorbid conditions related to FASD, the challenges in everyday life for families with FASD children, and the different levels of interventions for affected individuals.

## Group work

The day continued with group work. The participants were divided into three groups – clinical work, associations/non-governmental organizations (NGOs), and research. The participants were to choose their own group related to their occupation and/or field of interest. The task was to come up with solutions (and a plan) for up to three of the identified problem areas detected in the group work of day one (see table 1). The solutions (and plans) (see table 2) were presented for all participants at the later plenary discussion of the group work.

**Table 2: Results of the group work**

Group	Solution
Clinical work	<ol style="list-style-type: none"><li>1. How to identify the right children<ol style="list-style-type: none"><li>a. Specialist services<ol style="list-style-type: none"><li>i. Education</li></ol></li></ol></li><li>2. High-risk groups<ol style="list-style-type: none"><li>a. Should be followed<ol style="list-style-type: none"><li>i. Primary or/and secondary care</li></ol></li></ol></li></ol>

	<ul style="list-style-type: none"> <li>ii. Screening programme</li> <li>iii. Right to exam/treatment (Cerebral Palsy, autism)</li> </ul> <p>3. How to secure multidisciplinary assessment?</p>
<b>Associations / NGOs</b>	<ul style="list-style-type: none"> <li>1. A platform for sharing material and information</li> <li>2. Campaign to increase general knowledge</li> <li>3. Workshop in Norway to share materials etc.</li> </ul>
<b>Research</b>	<ul style="list-style-type: none"> <li>1. Nordic platform <ul style="list-style-type: none"> <li>a. Content: Ongoing research projects, published research, pamphlets for patients and relatives, practical information, organizational thoughts, conferences/meetings</li> <li>b. Administration: Nordic Welfare Centre, FAS-Föreningen, collecting and classifying information, board - one from each country</li> <li>c. Economy: Whoever provides the platform</li> </ul> </li> <li>2. Common Nordic research <ul style="list-style-type: none"> <li>a. Projects based on existing registers</li> <li>b. New registers / Database</li> <li>c. Specific new projects</li> </ul> </li> <li>3. Steering committee (for common Nordic research) <ul style="list-style-type: none"> <li>a. 1-2 members from each country</li> <li>b. The first meeting in Denmark in March 2020</li> <li>c. Funding from the Nordic Federation of Societies of Obstetrics and Gynecology (NFOG) fund</li> </ul> </li> </ul>

## Expectations that were met

During the wrap up session, the listed expectations from day one were discussed. Some of the expectations that were met, were also part of the solutions the groups came up with (see table 2). As a result of the discussion, the organizers see that following expectations for the expert meeting were met:

- Collaboration, networking and new contacts
- Support from Nordic Welfare Centre to focus on FASD
- Research collaboration
- New ideas in general
- How can we support people with FASD

# Outcomes of the expert meeting

The expert meeting ended up with the four specific outcomes, which will be the focus for the next steps in the Nordic collaboration in the field of FASD, initiated by the Nordic Welfare Centre. Each of the outcomes (see table 3) has a working group in lead (here stated by the country they represent, except the Nordic Welfare Centre), and they are responsible for taking the first steps in the continuous work.

**Table 3: Outcomes of the expert meeting**

<b>Outcomes</b>	<b>Country in lead</b>
<b>Nordic workshop at the European conference on FASD 2020</b> (E.g. Nordic PhD students presenting their research)	Norway
<b>Nordic research collaboration</b> (Planning the first meeting in March 2020)	Denmark
<b>Platform to share knowledge on FASD from the Nordic countries</b>	Sweden
<b>A report with a focus on interventions for people affected by FASD</b>	Nordic Welfare Centre

# Highlights of the expert meeting

From the organizers' perspective, the meeting offered a prominent platform to meet experts who work in the field of FASD in the Nordic countries. The meeting generated discussion and future directions and ideas for collaboration. Participants were active in group discussions, and shared experiences and practices from the Nordic countries. The group discussions resulted in concrete future directions and ideas on collaboration.

The results of the evaluation from the expert meeting indicated that the meeting was really appreciated. According to the results, the meeting met the expectations of the participants, and the expert meeting was found useful to a large extent. Also, the Nordic perspective was useful for one's own work. As future suggestions, Nordic meetings and collaboration are needed. It was also suggested that more people need to be involved in these expert meetings and in the Nordic collaboration.

As discussed at the wrap up session, it is positive that there were representatives from each Nordic country and that the participants have shown interest in the field of FASD. However, more people are needed from different occupational groups, especially pediatricians and obstetricians as also highlighted in the evaluation.

The participants of the expert meeting also highlighted the following issues as take-home messages:

- It is expensive not to do anything within the FASD field.
- Only a few exposed individuals receive a diagnosis. Without the diagnosis, any prevalence estimates are difficult to establish. Without a clear picture of the size of the problem, it is difficult to get support and funding from health authorities.
- There is only one FASD competence center in the Nordic countries that has the competence to diagnose exposed individuals and train healthcare professional regarding FASD.



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