

**Statement from The National Organisation for FASD
on the NICE Quality Standard on FASD
16 March 2022**



The new NICE Quality Standard on FASD is a massive step forward for the FASD's UK community. Taken with other recent policy steps, including importantly the DHSC FASD Health Needs Assessment, it represents a recognition that the struggles of people with FASD are real. The country must take note and local decision-makers should take action.

Ensuring a proper assessment for those at risk of FASD and a full neurodevelopmental assessment for those with prenatal alcohol exposure and/ or sentinel facial features are important steps forward. And the statement on care management plans is potentially transformational. Hopefully this will help to ensure people with FASD and their families won't face the post-diagnosis period without a way forward.

Giving women information they need to make informed choices and ensuring fetal alcohol exposure does not go unnoticed will help create healthier pregnancies and brighter futures. It isn't about shaming or blaming, but about getting the right supports in place where needed and helping women to make truly informed choices.

Woven throughout the Quality Standard are references to the need for local areas to ensure professionals are trained up appropriately. They will have to show this via measurable indicators. That one point alone will change lives. It's a massive task and decision-makers need to address how to do this to ensure the needed competence. National FASD has resources to help as do other independent organisations who are members of the FASD UK Alliance.

We all should beware of specialist interest groups twisting this narrative about the risks of alcohol in pregnancy or FASD deniers saying there isn't enough evidence. They have lost this battle and the country will be healthier as a result. The fact that the Quality Standard is silent on the issue of recording in a child's records doesn't mean that it can't be. Women can help ensure their children have brighter futures. A new poll of 2000 women shows that the overwhelming majority would not object to giving permission for alcohol exposure to be noted in the child's records to help with early diagnosis and appropriate support later if needed.

The NICE Quality Standard will set in motion changes that sadly may yet take some years to work through the massive NHS system. It focuses on children and young people. The very young identified at birth as being alcohol exposed may still fall through the cracks if their early development is not carefully tracked. There remains an unconscionable hole still when it comes to diagnosis and support for adults. The training needed will take time as there isn't yet enough available and we have to guard against new training that is not based on the latest understanding. These battles are ongoing.

But everybody in the FASD community will sit a little bit taller today. FASD has been recognised. People with FASD and their families have been seen and heard. It's a new day. Now our local, regional and national decision-makers need to understand this and take action side-by-side with the FASD community – they need to engage us all in their discussions and deliberations as we work together to create better tomorrows. Political will is needed to make these improvements happen.

FOR MORE INFO: National FASD has just concluded a series of nine roundtables with more than 60 national experts, clinicians, policy maker, clinicians and people with lived experience to discuss ways to operationalise the improvements called for by NICE and the DHSC. The report will be released 21 March 2022 at a special event in London.

Media please contact joanna.buckard@nationalfasd.org.uk for more information. Others can register for the event livestream here: <https://www.eventbrite.co.uk/e/294537639007>