NATIONAL ORGANISATION FOR FASD

GOVERNMENT MUST ENSURE PEOPLE WITH FASD ARE NOT DISPROPORTIONATELY AFFECTED BY PLANNED CHANGES

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The National Organisation for FASD is increasingly alarmed that the futures of people with FASD (Fetal Alcohol Spectrum Disorder) are being put at greater risk by changing priorities and cuts in support proposed by the Government.

Amid significant reductions in disability benefits and with changes in special educational needs policies, healthcare structures, adoption and special guardianship support, and budget priorities, people with diagnosed and undiagnosed FASD—already identified as needing more support—face potentially devastating outcomes.

The National Organisation for FASD urges the Government to uphold the necessary improvements in quality of care identified in the National Institute for Health and Care Excellence (NICE) Quality Standard 204 and the DHSC FASD Health Needs Assessment. These guidelines emphasise the importance of training for professionals to understand how FASD manifests across the lifespan, providing accurate information about alcohol risks during pregnancy, and ensuring access to diagnostic assessments, including neurodevelopmental evaluations for those affected by prenatal alcohol exposure.

Without the training recommended by NICE and DHSC, people with FASD and their families may not receive fair assessments for benefits, support, and appropriate educational provisions. We fear people with FASD are increasingly at risk of being failed by the very systems meant to assist them.

Ignoring the necessary steps on FASD outlined by NICE and DHSC undermines the Government's commitment to prevention, early intervention, and cost-effective programs. Effective improvements in education, health, and social care, as well as effective spending in these areas, require acknowledging the needs of the estimated 2-4% of the population affected by lifelong neurological impairments from prenatal alcohol exposure. Without proper diagnosis and support, up to 90% of people with FASD may face severe mental health challenges, support for which is being severely curtailed. Our research shows the NHS is not fully implementing NICE Quality Standard 204, and even FASD diagnosis is not being consistently commissioned.

A lack of understanding about FASD among professionals, especially those making decisions about benefits, heightens the vulnerability of those with diagnosed and undiagnosed FASD under the new policies. The consequences of neglecting this population are not only unjust but also short-sighted.

We reject claims that funding for proactive changes recommended by NICE and DHSC is unavailable, even in financially challenging times. With projected alcohol duties of £12.4 billion in 2024-25, we renew our call for just 0.2% of these duties to fund an FASD Prevention and Response Fund. Targeted, efficient spending will significantly reduce wasteful spending already made in an unfocused way due to lack of recognition of FASD. This investment would align the UK with similar nations and help those affected by prenatal alcohol exposure live meaningful lives rather than face lives of despair, as research warns will happen when they fall through shrinking safety nets.

On behalf of people with FASD, their families, and dedicated professionals, we urge the Government to uphold its commitments to support outlined in NICE Quality Standard 204. We call on leaders to meet with individuals with FASD, listen to their concerns, and ensure they do not disproportionately suffer from the Government's sweeping cuts and changes. We stand ready to assist.