

## Statement on Closure of the Centre for FASD

*Highlights need for national strategy  
to meet rising demand for FASD assessment*



8 February 2022 - The National Organisation for FASD is deeply saddened by today's news of the coming closure of the Centre for FASD led by Dr Cassie Jackson in Suffolk. The Centre has been filling a gaping hole in national capacity for FASD diagnosis, by providing assessment for more than 100 people per year. With its closure, the diagnostic capacity nationally is being set back by several years.

As a private clinic the Centre was one of the few in the country where Adoption Support Funds were being used for FASD diagnosis as part of a wider assessment. This model was recently highlighted in a Parliamentary question on 31 January as proof of Government's support for families affected by FASD. The reality however is that new rules governing Adoption Support Agencies and the cap of the ASF funding at £2500 makes this model financially unsustainable (by contrast the National FASD Clinic charges more than £4000 per assessment but does not accept ASF funding). The ASF is not fit for purpose for FASD assessments, which is of particular concern since a disproportionate number of those who are adopted are at risk of FASD.

As a result of this lack of joined-up-thinking by policy makers and despite her strong and continuing advocacy for those with FASD, Dr Jackson has been forced to announce the Centre's closure in April. National FASD is pleased, however, to know that she will continue to serve on our Experts Committee and will continue to be involved in supporting those with FASD in various ways in her coming work. Anyone who has met Cassie knows she has a contagious passion to provide better services and support for people with FASD and we know she will continue to push for needed changes.

Families across the UK are reeling from this news. For some, the Centre for FASD represented their only option for being able to get an assessment for their loved one given the dearth of commissioned services for FASD, highlighted in our report "[A Crisis of Commissioning](#)." Every day that families must go without understanding the brain-based challenges their loved ones face due to prenatal alcohol exposure leads to complications, delayed support at school and in the community, and risks compounding mental health challenges.

Those families who are unable to be seen by the clinic should as a first step contact their GP and local paediatric services to request assessment locally where possible. Some others can seek referral to the National FASD Clinic led by Prof Raja Mukherjee in Surrey. We understand fully that for many this may mean years of delay and underscore again that this lack of services is totally unacceptable.

There is an immediate need for national thinking on how to fill the gap in diagnostic services for FASD. While we have called 2022 the 'tipping point' since the major public health bodies are finally now lined up regarding the urgency of FASD (which a [recent study](#) by the University of Salford shows affects approximately 3% of the population), the [NICE Quality Standard on FASD](#) has been delayed too long.

It's time for NICE to announce its new timeline. It's also beyond time for leaders to set out their plan for how to respond to FASD, starting with the priority areas identified in the [DHSC FASD Health Needs Assessment](#) and to provide guidance and funding on how implement the changes needed to ensure individuals with FASD and suspected FASD and their families won't continue to be failed by health services.

The National FASD Experts Committee has been convening a series of policy roundtables on "The National Perspective on Ramping up FASD Prevention, Diagnosis and Support Services" involving dozens of experts, practitioners, policy makers, commissioners and people with lived experience. They will be issuing a report in March identifying ideas and challenges.

For more information about FASD diagnosis and wellbeing and parenting strategies that might prove helpful in the meantime while seeking diagnosis, see [www.nationalfasd.org.uk](http://www.nationalfasd.org.uk).

This news may be distressing for many.

Please reach out to the independent FASD UK Alliance support groups across the country. To find a local group near you: <https://fasd-uk.net> (These are not affiliated with National FASD, we are a sister organisation in the Alliance.)