NOFAS-UK has a new report

The report is about how the NHS fails to provide services for those with FASD. This report focuses mostly on England.

Hundreds of Clinical Commissioning Groups (CCGs) across England are responsible for FASD services, according to statements ministers have made in Parliament.

"Responsibility for commissioning Fetal Alcohol Spectrum Disorders (FASD) services lies with clinical commissioning groups," said Steve Brine, when he was Health Minister, 19 February 2019
NOFAS-UK sent Freedom of Information Requests to all CCGs and NHS Trusts and summarised the replies in the new report.

In England, once a CCG commissions services, NHS Trusts provide those services to people.

But with FASD, this isn't happening. Partly because too few doctors have FASD training and partly because there is no agreed plan (or 'pathway') for diagnosis and support.
Freedom of Information responses showed CCGs are NOT providing enough FASD services.

- **Does the CCG have a policy for commissioning services for FASD?**
  - Yes: 8.43% (14)
  - No: 91.57% (152)

- **Does the CCG provide services for diagnosing FASD in children?**
  - Yes: 21.69% (36)
  - No: 78.31% (130)

- **Does the CCG provide services for diagnosing FASD in adults?**
  - Yes: 13.86% (23)
  - No: 86.14% (143)

- **Is the CCG involving individuals with FASD or their caregivers in planning or developing proposals?**
  - Yes: 10.24% (17)
  - No: 89.76% (149)

- **Is there a lead person in the CCG on FASD?**
  - Yes: 18.67% (31)
  - No: 81.33% (130)

Is the NHS Trusts/Health Board providing post-diagnostic care for FASD?

People with FASD deserve better.
People with FASD, their families and carers are "stakeholders".

Policy makers are supposed to listen to stakeholders.

Recently they have been hearing our voices about FASD. They are trying to decide how to improve services.

Adults and teens with FASD have had an important part in this process, especially in a meeting with Deputy Chief Medical Officer Gina Radford and other senior policy makers in October 2018 and in meetings in Parliament with Bill Esterson, MP, Baroness Hollins and others.

Change is coming. NOFAS-UK and other groups in the FASD UK Alliance have been urging action from policy makers.

All people with FASD - adults and children - have a right to diagnosis and support with dignity.

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