FOR PARENTS & CARERS

While You Wait

Your child does not need a diagnosis to get support. Here is what you can ask for now.

FASD Compass · fasdcompass.co.uk/while-you-wait/

Waiting lists for FASD assessment can be long. The good news is that **your child does not need a diagnosis to get support**. In England, neither the legal definition of special educational needs nor the definition of disability requires a diagnosis (IPSEA). Support should be based on what your child needs.

At School or Nursery

🏫 SEN support

- [ ] Ask for a meeting with the SENCO (special educational needs coordinator)
- [ ] Share your notes and any reports, and explain the difficulties you see at home
- [ ] Ask what SEN support the school will put in place, and how it will be reviewed
- [ ] Share the FASD Compass teachers page for classroom strategies

📄 Education, Health and Care (EHC) needs assessment

If SEN support is not enough, you can ask the local authority for an EHC needs assessment yourself, at any time. You do not need the school's agreement or a diagnosis.

- The local authority must reply within 6 weeks
- If it agrees to assess, a final EHC plan must be issued within 20 weeks of your request
- IPSEA has a free template letter to help you ask

🤝 Free, impartial advice

Every area in England has a SENDIASS (special educational needs and disabilities information, advice and support service). It is free, and you do not need a diagnosis to use it. Find your local service.

In Scotland, Enquire advises on additional support for learning. In Wales, SNAP Cymru advises on additional learning needs.

Money and Practical Help

💷 Disability Living Allowance (DLA)

DLA for children is for children under 16 who need much more looking after than other children of the same age, or who have difficulty getting about. The needs must have lasted at least 3 months and be expected to last at least 6 months. It is based on your child's needs, not a diagnosis. Young people aged 16 and over apply for Personal Independence Payment (PIP) instead.

🏠 A parent carer needs assessment

You can ask your council's children with disabilities team for an assessment of your own needs as a carer. It looks at your wellbeing, work and family life, and can lead to support such as short breaks. Find your local council. Your council's Local Offer website also lists local SEND services and support groups.

At Home

💡 Strategies that help now

FASD-informed approaches help many children, with or without a diagnosis. See the **FASD Compass parents page** and **National FASD parenting tips**.

🗂️ Keep the referral moving

- [ ] Keep copies of every letter, report and email
- [ ] Write down the date of each referral and who made it
- [ ] If you have heard nothing after 6 to 8 weeks, ask your GP practice to check the referral was received
- [ ] Keep a short diary of difficulties and what helps, to share at the assessment

Support for You

📞 Helplines

- **National FASD:** 0208 458 5951
- **Contact**, for families with disabled children: freephone 0808 808 3555. You do not need a diagnosis.
- **Carers UK**: 0808 808 7777

👨‍👩‍👧 Other families

Talking to families who understand can make a real difference. The FASD UK Alliance links local support groups across the UK. **Find local support**.

🚨 **If you are worried about safety right now**

Call NHS 111 for urgent advice, or 999 in an emergency.

Sources: IPSEA: ipsea.org.uk · DLA for children: gov.uk/disability-living-allowance-children · Find your local SENDIASS: councilfordisabledchildren.org.uk · Contact: contact.org.uk · National FASD: nationalfasd.org.uk

Last reviewed: November 2026 by Dr Inyang Takon, Consultant Neurodevelopmental Paediatrician. For information only. This page does not replace advice from your own doctor.