

# LIVING WITHOUT A DIAGNOSIS

This fact sheet has been written by parent carers for parent carers



Getting a diagnosis that explains your child's additional needs may take a long time or may never be fully resolved. Some families will get vague diagnostic labels like 'global development delay', some will start off being told their child has one thing, only to be told they have another in later years.

Living with this kind of uncertainty can be frustrating and upsetting. It can be more of a struggle to get help or find a community of other parents who understand your experiences.

Whatever your situation, don't delay asking for support. Your child should be able to access the help they need, with or without a diagnosis.

## Why is there no diagnosis?

There is a huge variation in what is considered normal development and it may be that your child, although very different from their peers, does not meet the diagnostic threshold for a specific condition or difference. For example, children and young people may be described as 'borderline' for conditions such as ADHD or autism, or that they have traits of a condition but do not warrant a full, formal diagnosis. It may be that the criteria used to diagnose a condition need updating; until quite recently, for example, clinicians were consistently failing to diagnose girls with autism or ADHD because they were only used to recognising how these neuro-differences presented in boys.

Sometimes it is too early to make a diagnosis and clinicians will want to wait until a child has reached a particular age before conducting assessments or coming to any conclusions. For other children, their condition and set of symptoms may be so rare that clinicians are unable to put a name to it. Even with genetic testing, it is not always possible to get answers or a diagnosis (see our separate fact sheet, *Rare syndromes*, for more on this).

Remember too that every child or young person is an individual and their additional needs or symptoms will be different or may fit more than one condition.

## Strategies for coping with not getting a diagnosis

When you are struggling with not having a diagnosis the following strategies may help.

**Focus on the needs not the label** – it's easy to expend a lot of energy trying to get a diagnosis but don't let it distract you from working out what help your child needs, as this is what will make the biggest difference to their daily lives.

**Don't wait for a diagnosis before you ask for help.** Even if your child grows out of their difficulties this will help them in the meantime and if they don't, you'll be glad you acted quickly.

**Find an explanation of their differences that you can use.** You might not be able to tell friends 'my child has such and such condition' but perhaps you can say something like 'his instincts are not like other children's' or 'she has difficulties with understanding social situations'.

**Keep a written list of examples of your child's differences** and take it along to school meetings and medical appointments and assessments. This saves you having to remember evidence on the spot and makes it less stressful.



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**Think about claiming Disability Living Allowance for your child.** You don't need a diagnosis to qualify for financial help - it's all about the extra support your child needs compared to other children — and getting DLA is a passport to other benefits too. See how Amaze can help with DLA in Ask About below.

**Ask for and keep written statements about your child's needs.** You can ask health professionals or your child's school for written details of your child's difficulties and differences and how they impact their daily life. You will need this kind of evidence for claiming Disability Living Allowance or other benefits and grants.

**Watch for change, monitor your child's progress.** They might not have met the clinical criteria for a particular diagnosis at three, but if they're still demonstrating certain behaviours at seven, they may now be diagnosed.

**Join a parent support group.** It can be really helpful to connect with other parents who have similar experiences. Amaze runs lots of groups for parent carers of children with additional needs, or you can join an online group. See Ask about below.

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### Types of support

Similar strategies and techniques (such as those for communication) work for many different conditions, and these can be adapted to help your child's needs, regardless of a diagnosis.

You may get support from the following services:

- **Education** - your child is entitled to extra support and/or adaptations to help them at nursery, pre-school, school or college.
- **Occupational Therapy (OT)** - can help your child develop their hand skills and can identify solutions to help your child develop their independence with every day tasks such as dressing and eating and drinking.
- **Physiotherapy** - an important intervention to help a child develop and maximise their range of movement and posture.
- **Social Services** - ask for an assessment of both your child's needs and a Carer's Needs Assessment for you.
- **Speech and Language Therapy (SALT)** - specialist support provided by a therapist to help build language and communications skills.

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### Ask about

- **Amaze SENDIASS (Special Educational Needs and Disability Information, Advice and Support Service)** offers impartial, confidential advice on anything to do with SEND for 0 to 25 year olds. Parents, carers, children and young people under 25 with SEND living or going to school in Brighton & Hove or East Sussex can use the service. Email [sendiass@amazesussex.org.uk](mailto:sendiass@amazesussex.org.uk), call 01273 772289 or visit <https://amazesussex.org.uk>
- **Amaze - ND Family Support Service** supports families with the challenges they may face when their child or young person is on the neurodevelopmental pathway for conditions like autism, ADHD, tics/Tourette syndrome and foetal alcohol spectrum disorder. Your child does not need a diagnosis to get support. Email [NDP@amazesussex.org.uk](mailto:NDP@amazesussex.org.uk) or refer yourself to the service here <https://amazesussex.org.uk/nd-family-support>



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- **Amaze - Parent groups & befriending** – one to one befriending and regular support groups for parent carers across Brighton & Hove and East Sussex, including groups with a focus on neurodevelopmental differences like autism and ADHD. For details of all our groups, visit <https://amazesussex.org.uk/parent-groups-and-befriending>, call: 07484 051755 or email: [marie@amazesussex.org.uk](mailto:marie@amazesussex.org.uk)
- **Other parent support groups.** You can get details of all your local parent carer support groups on the Local Offer, Family Information Service or Community Directory for your area. For *Brighton & Hove* parent carer support groups visit <https://www.brighton-hove.gov.uk/directories/special-educational-needs-and-disability-send-support>. For *East Sussex* parent carer support groups, visit <https://1space.eastsussex.gov.uk/>
- **Child Development Teams** - consultant paediatricians, specialist nurses and therapists who assess and support disabled children up to 11. Ask your GP, health visitor, your child's school or another professional working with your child for a referral. In Brighton & Hove this service is based at the **Seaside View** Child Development Centre. In East Sussex, it is based at **Community Paediatrics Parkview** in Bexhill, Kipling Outpatient Dept in Hastings and satellite clinics. Therapies and equipment services in East Sussex are provided by the Children's Integrated Therapy and Equipment Service (CITES). Contact Therapy One Point on 0300 123 2650 or visit <https://www.eastsussexchildren.nhs.uk/about/childrens-integrated-therapy-services>.
- **Disability Living Allowance (DLA)** – if your child's care or mobility needs are significantly greater than the needs of their peers you may be able to claim DLA for them. Visit [www.gov.uk](http://www.gov.uk) and search for DLA. Amaze can also give you advice and support with making a claim. Visit <https://amazesussex.org.uk/benefits-advice> or call our SENDIASS advice line on 01273 772289.
- **Compass or i-go leisure discount cards** – 0 to 25 year olds with SEND who join the Brighton & Hove Compass or East Sussex i-go disability register get a free card that gives them access to leisure discounts and offers across the region. You don't need a specific diagnosis to get a card but most children on the registers get DLA or have an Education, Health and Care Plan. For the Brighton & Hove Compass Card scheme visit [www.compasscard.org.uk](http://www.compasscard.org.uk). For East Sussex i-go, visit <https://igo.eastsussex.gov.uk/>

### Further reading and useful links

- **Amaze's fact sheet on Rare Syndromes.** Download from our website at <https://amazesussex.org.uk/resources/fact-sheets>
- **Contact** publishes a parent guide to living without a diagnosis on their website <https://contact.org.uk/wp-content/uploads/2021/03/Living-without-a-diagnosis.pdf>
- **Local Offer:** comprehensive online listing of all services for families with children and young people with special educational needs and disabilities (SEND) in your area. See Brighton & Hove Local Offer: <https://www.brighton-hove.gov.uk/special-educational-needs-and-disabilities/school-age-children> and East Sussex Local Offer: <https://localoffer.eastsussex.gov.uk>
- **Syndromes Without a Name (SWAN UK)** – advice, information and private online forum for parents with a child with an undiagnosed genetic condition. Visit <https://geneticalliance.org.uk/support-and-information/swan-uk-syndromes-without-a-name>

