

LIVING WITHOUT A DIAGNOSIS

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



When a child has difficulties but doctors are not able to give parent carers a firm diagnosis it can be very distressing and frustrating. Often, families say they feel alone; it is hard to access support and the future remains uncertain as they don't know how their child's condition will develop. The organisation 'Genetic Alliance UK' estimates that as many as half of children with learning disabilities do not have a definitive diagnosis.

For many parent carers, not having a firm diagnosis can feel very upsetting. One of the biggest concerns is that without one they will be unable to access support, but this is not the case – the support a child is entitled to is based on their needs rather than whether they have a diagnosis or not.

First signs

For many parents, the first signs that their child may have difficulties can be if you notice they seem different to their peers. It could be that they fail to meet developmental milestones at an appropriate age in one of the following areas:

- **Motor skills** - gross motor skills, such as sitting up, crawling and walking and fine motor skills, such as picking up objects.
- **Speech and language** - babbling, for example, and imitating sounds, as well as understanding what people are communicating.
- **Cognitive skill** - the ability to learn new things, to remember them, to process information and organise thoughts, for example.
- **Social and emotional skills** - interacting with others, controlling emotions, and understanding the needs and feelings of others.

When there are no answers

If your child is having difficulties, you will want to find out why. But it's not always this straightforward. Sometimes clinicians are unable to give you a reason and name for your child's condition. This can be very frustrating, as well as frightening. However, there are a number of reasons why this happens. Every child's features and symptoms will be different. Sometimes they may fit more than one condition.

Other children may be 'borderline' for conditions such as ADHD or Autism – they may have traits of the condition but not meet the criteria for a diagnosis or sometimes it is too early to make a diagnosis. 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**).

What happens next?

Not having a diagnosis can be upsetting and frustrating. You may feel that your child's difficulties are your fault because you can't put them down to a recognised condition. Or you may feel that you aren't entitled to ask for support, but this is not the case. Your child should be able to access the same services as children with similar needs who have a diagnosis. It is also worth remembering that many strategies and techniques (such as those for communication) work for many different conditions, so these can be adapted to help your child, too.

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Types of therapy

Depending on your child's needs, you could 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** - contact the **Specialist Community Disability Service** on **01273 295550** to 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.

Ask about

- **Amaze** – the **Special Educational Needs and Disability Information, Advice and Support Service (SENDIASS)** offers impartial, confidential advice on anything to do with special educational needs and disabilities for 0 to 25 year olds. Parents, carers, children and young people under 25 with SEND living in Brighton & Hove or East Sussex can use the service. Email sendiass@amazesussex.org.uk, call **01273 772289** or visit our website at <https://amazesussex.org.uk>
- **Compass Card** – a free leisure discount card administered by Amaze for 0 to 25 year olds with SEND who are registered on the compass. You don't need a specific diagnosis to get a card but most children on the compass get DLA or have an EHC Plan. Go to: www.compasscard.org.uk, email Amaze at: compass@amazesussex.co.uk or call: **01273 772289** (Brighton & Hove) or **0300 123 9186** (West Sussex).
- **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 and search for DLA. Amaze can also give you advice and support with making a claim. Call our helpline: **01273 772289** or visit our website: amazesussex.org.uk.
- **Seaside View Child Development Centre** – this is where many children are diagnosed and where health professionals such as paediatricians and therapists work together to support and treat your child. Assessments will usually be via a health or education professional but you can contact Seaside View directly on: **01273 265780**.
- **Parent support groups** – there are many parent led groups for children with disabilities in Brighton & Hove. You can find a list of local groups in Brighton & Hove at: amazesussex.org.uk/parent-carers/info-advice-parent-carers/survival-strategies/parent-support-groups

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** - for further information search for 'living without a diagnosis' on their website: contact.org.uk.
- **Local Offer** – the local authority's online listing of all the services and support that are available to families with children with SEND in the area. Visit new.brighton-hove.gov.uk/special-educational-needs-and-disabilities
- **Syndromes Without a Name (SWAN UK)** – go to: www.undiagnosed.org.uk.

