

# 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 report feeling isolated; it is hard to access support and the future remains uncertain as they don't know how their child's condition will develop. According to the organisation 'Syndromes Without a Name' (SWAN UK), as many as a third of children with special needs do not have a clear diagnosis or name for their condition. The figure may be as high as 50 per cent of children with learning disabilities.

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 need rather than having a diagnosis.

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## 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.

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## 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').

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## 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 Integrated Child Development and Disability Service on **01273 265780** 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

- **Information, Advice and Support (IAS)** - Amaze supports families of children and young people with SEN and disabilities in Brighton and Hove. You don't need to have a specific diagnosis to get support. We have a helpline, publications and a website. We also run workshops and courses and can offer one-to-one support with EHC planning and making DLA and PIP claims. Call Amaze on **01273 772289** or visit **www.amazebrighton.org.uk**
- **Compass Card** - a free leisure discount card administered by Amaze for 0 to 25 year olds registered on The Compass who live or go to school in Brighton and Hove or West Sussex, or who are looked after by social services in these areas. You don't need a specific diagnosis to get a card but most children on The Compass get DLA or have a Statement of SEN or Education, Health and Care Plan. Call Amaze on: **01273 772289**
- **Independent Support** - Amaze's Independent Supporters provide extra advice and support to young people and parent carers who are going through the process of getting an EHC Plan in Brighton and Hove and Sussex. For Brighton and Hove Independent Support, call: **01273 772289**. For Sussex Independent Support, call: **0300 123 7782**.
- **Integrated Child Development and Disability Centre** (Seaside View) - where health, education and social care professionals 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**
- **Making a claim for DLA** - you don't need a specific diagnosis to claim Disability Living Allowance for your child - you just need to prove that your child's care or mobility needs are significantly greater than the needs of their peers. For further information visit: **www.gov.uk/dla-disability-livingallowance-benefit/overview** or call the Amaze helpline on: **01273 772289** - we can offer information and advice on making a claim.

### Further reading and useful links

**Through the Maze** - Amaze's handbook for parent carers of children and young people with SEN and disabilities (0-14) includes lots of information on education, money matters, social care, health, leisure and more. There's a section all about diagnosis and how to cope if you don't get one. It's free to parent carers of children who live or go to school in Brighton and Hove. Call the Amaze helpline to request a copy on **01273 772289**.

- **Contact a Family** - for further information search for 'living without a diagnosis' on their website: **www.cafamily.org.uk**
- **What is DLA?** and **'Tips for claiming DLA'** - fact sheets from Amaze/Reaching Families can be downloaded at **www.amazebrighton.org.uk/resources/publications/fact-sheets**.

