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How to support your child with a learning disability

All parents and carers have worries and concerns about their children at some point. For those with children who have learning disabilities, there can be further concerns about supporting your child's development, communication and independence.

Across the UK population, [more than 350,000 children](#) – approximately 2.5% of under-18s – have a learning disability. They can range from mild to profound and multiple learning disabilities (PMLD). Some people can interact with others and carry out most everyday tasks with little difficulty, whereas others need far more care and support with communication, mobility and looking after themselves. Learning disabilities differ from learning difficulties like [ADHD](#), [dyslexia](#) and [dyspraxia](#) in that learning difficulties do not affect general intellect.

Robert's daughter Eleonore, 29, was born with a genetic disorder. "The main effects of the disorder are that she is what's known as deafblind. She's [visually impaired](#) and [hearing impaired](#). From the age of eleven, she's had bouts of unpredictable and sometimes uncontrollable [epilepsy](#). Eleonore has profound and multiple learning disabilities," says Robert.

Independence

Eleonore no longer lives with her parents but has carers who live with her to manage every aspect of her life, including communication, activities, shopping and household chores.

Whilst Eleonore needs support to carry out most activities, Robert was taught to encourage her to have as much independence as possible in the early stages of her life. "In order to feed Eleonore with a bottle once she stopped [breastfeeding](#), I used to sit on the floor, have Eleonore between my legs with her back against my stomach, hold the bottle with my hand over her hand and put the teat in her mouth.

"The health visitor came along and said, 'You can stop that!' What I was doing was not giving Eleonore the means of doing things for herself. A health visitor who'd never heard of the syndrome challenged our way of supporting Eleonore. That was probably one of the earliest and most helpful things that could happen for us."

Key was never underestimating what Eleonore was - or would be - capable of, including by not comparing her progress or ability to other children with similar conditions. "I think one of the reasons why Eleonore can walk unaided at times is because at a very early stage we thought, just because she can't walk now, nobody's said that she won't be able to. So let's try to help her," says Robert.

Supported independence allows people with learning disabilities to make independent choices in a controlled, safe environment - for example, choosing clothing or food.

"Intellectually, Eleonore might not understand what being given a choice is," Robert explains. "But you allow her to make a choice and then you go with it. She's never given the option to do a safe thing and a dangerous thing. She's given the option to do two safe things. The alternative is to do everything for her."

Respite and care

It goes without saying that being a carer can put pressure on parents and families, whether that's adjusting to caring for another person or coping with the strain of working with local authorities to get support for your child. Some families need additional help, including respite.

"Short breaks, or respite, are an important service for families with disabled children," explains Margaret Gould, Information and Advice Officer at the learning disability charity [Mencap](#).

"They can provide the family with a break from caring, whilst also benefiting the child with a learning disability by giving them the opportunity to experience something interesting and fun. This could be going to new places, meeting different people or taking part in an activity that they enjoy independently of their family." Respite allows families to manage other responsibilities, including sleep, domestic chores, leisure activities and spending time with other family members.

For information about the respite services in your area, take a look at what is offered locally. "By law, each local authority must publish a Short Break Service Statement, which sets out the short break services available in their area, the eligibility criteria for accessing those services and how those services meet the needs of carers in the area," continues Gould.

"In the majority of cases the eligibility criteria will require an assessment of need in order for a child to access a short break provided by the local authority."

Communication

Communication takes many forms. It's a case of figuring out what works for you and your child. Speech therapy, body language and sign language can all help. In Robert's experience, learning how to communicate with Eleonore took trial and error.

"My wife and I originally started to learn British Sign Language (BSL). But because BSL is a language with its own grammatical construction, it was too complicated for Eleonore. We tend to use some Makaton signs as sign-supported English," he says. Makaton is sign language based on BSL that is sometimes used in conjunction with speech, and in English grammatical word order.

A speech and language therapist helped Robert to understand that perfect grammar and full sentences were less important than Eleonore being able to get her meaning across.

"If Eleonore, for example, signed 'cake', I would say, 'No, you say, 'I want some cake please', and sign all that out," explains Robert. "You might be trying to teach Eleonore the grammatical construction of a full sentence, but you know what she wants. Show her that the moment she's made the sign, to her ability, you've understood it and you respond to it. Let her see that her communication is valid."

Focusing on functional sign language, gestures or words can make communication easier. "The fact that she now can't say 'one, two, three, four, five' is irrelevant - it's not functionally useful in her daily life," he says. "We were helped to understand how to use communications, signs and words which are useful to her. It was only as Eleonore developed you realised how much speech she was actually capable of."

School

When any child reaches school age, finding the right school can be a challenge. Knowing the right people to talk to within the school can make all the difference, says Gould.

"It's really important to work with the school to achieve the best possible outcome for your child. Talk with the class teacher, the head teacher and the special educational needs co-ordinator (SENCO). They are in a position to fully assess your child in the classroom and evidence any additional support needs."

When the school is unable to support a child through the usual channels, Education, Health and Care (EHC) plans come into place. "The advantage of EHC plans is that they offer a more holistic approach covering health and social care needs for someone in an educational setting, and they extend from 0 to 25 years for anyone who is in education," she continues. "The school can help prepare for an EHC assessment through an 'assess, plan, do, review' cycle for your child. You can find advice on your child's rights and resources to help you challenge education providers and local authorities on the [IPSEA website](#)."

Local services and financial support

"Know what the local authority is legally obliged to do, which is different from what you would like them to do" suggests Robert. Authorities have a legal responsibility to provide certain support. Often a social worker will be your point of contact. "Make friends with them, praise them when they do something good and give them ammunition to fight your case when you're not at the meeting."

You can find out what support is available in your area online. "Every local authority must now publish a 'Local Offer' of services and support available for children and young people with special educational needs and disabilities (SEND) from 0 to 25 years," says Gould.

[Research by Scope](#) found the average family with a child with a disability faces extra costs of £581 a month. There is some financial support available to support these costs, although you may need to seek help - for example, through [Citizens Advice](#) - to ensure that you receive the full amount you're entitled to. Charity [Turn2us](#) also provides a benefits calculator and grants.

"[Disability Living Allowance](#) (DLA) provides help towards the extra costs of bringing up a disabled child," explains Gould. "You can claim up to your child's sixteenth birthday, after which they will need to apply for [Personal Independence Payments](#) (PIP). DLA is split into a mobility component and a care component, and your child can be eligible for either or both components. Universal Credit is being rolled out across the country and will replace means-tested benefits like housing benefit, tax credits and income support.

"Your child is also entitled to a social services assessment of their needs, which is a pathway to specialist support. Most local authorities will have specialist departments called Children with Disabilities teams who are responsible for arranging practical support for children who meet eligibility criteria after assessment."

Your GP can also help with referrals to specialist services like speech therapy and physiotherapy. You can find further resources about supporting a child with a learning disability on the [Mencap](#) and [Contact](#) websites.

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