

Information leaflet

Supporting a child with a physical or sensory impairment or learning disability

In certain cases a Special Guardianship Order (SGO) may be made where a child has a physical or sensory impairment or learning disability.

The 2017 special guardianship guidance provided to local authorities, states that you must be considered for extra financial support if there will be a greater amount of money spent because of illness, disability, emotional or behavioural difficulties (see section 38(b) of that guidance).

This would be considered in the SGO support plan but if for any reason it wasn't covered you can have it reviewed through asking for an assessment of your support needs with your local children's services.

As the carer of a child with additional needs you are also entitled to all the support anyone else would get in your position – although it can be daunting to know where to turn to.

Here is a brief outline of all the ways you might be able to find out more about your new role, adapt to new responsibilities and access the help you may need.

Local offer

A good starting place is your local authority's Local Offer which is an information service for parents caring for children with special educational needs or a disability. The Children and Families Act 2014 states that every local authority should have one and that it should be kept up-to-date and publish parents' comments as to how useful it is.

The Local Offer should have a directory website covering a range of important information for your area including:

- Education, health and care provisions
- Training
- Travel to and from schools
- Provision for adulthood and independent living
- Finding employment

- Obtaining accommodation
- Participation in society
- Information about how to obtain an Education, Health and Care (EHC) needs assessment

What's an Education, Health and Care (EHC) needs assessment?

An EHC needs assessment looks at whether a child needs an Education, Health and Care (EHC) Plan. An EHC Plan is for children and young people aged up to 25 who need more support than is otherwise available. The plans identify the educational, health and care needs and if needed specifies what additional support should be put in place.

You may have heard of a 'statement of special educational needs' sometimes referred to as 'a statement'; this has been replaced by the EHC Plan.

Only a small number of young people receive an EHC Plan. You, the young person (if aged over 16 and under 25 years-old) or any professional such as doctors, teachers or even friends and family can request an assessment. If your child is given an EHC Plan then you might be entitled to a 'Personal Budget' to help you to get the support you need.

Personal Budget

A Personal Budget is essentially an agreement to give you money to spend on support for the child and can take the form of direct payments into your bank account so you can buy and manage services yourself or an agreement for someone else to manage it on your behalf – this could be a school, the local authority or even a family member or friend.

Information, Advice and Support

If you need further information and guidance you can contact your local Information, Advice and Support Services (IASS). They are able to give free, accurate and impartial information to parents, carers and children and young people with special educational needs and disabilities.

IASS was previously called PPS (Parent Partnership Services) but was renamed in the Children and Families Act 2014.

The scope of the information they cover is huge but includes:

- Local policy and practice
- The Local Offer
- Personal Budgets
- The law regarding Special Educational Needs and disability, health and social care.
- Advice for children, young people and parents on gathering, understanding and interpreting information and applying it to their own situation.
- Information on the local authority's processes for resolving disagreements, its complaints procedures and 'means of redress' (how it makes it up to you if something goes wrong).

Details about how to contact your local IASS can be found in your Local Offer.

Finding people in the same situation

Sometimes even impartial advice from professionals doesn't help with our need to share lived experiences, let off steam and shared our experience of seeking support.

Parent Carer Forums (PCF) are groups of parents and carers of disabled children who work with all the people in the lives of children with disabilities and additional needs – like local authorities and health providers – to ensure services meet their needs.

They don't advocate for individual families but instead try to improve the wider picture and situation for all families. PCF tend to attract invested, knowledgeable parents and carers and can be a great way to meet others who are in similar situations.

You can find your local PCF by visiting the National Network of Parent Carer Forums website.

Informal Support

Support can come in many forms and often the best way to find somebody to talk to is to visit disability service provisions in your area. Your Local Offer should include listings of sport and leisure activities in your area as well as local support groups, coffee mornings and drop-in sessions.

General information about disability

In some cases you may not know much about the disability your child has. It can be an overwhelming time but you can learn more about their conditions and the specific support that is available by contacting the main charity relating to your child's condition.

Key points

- Local authorities were issued guidance in 2017 stating special guardians must be considered for extra financial support if a greater amount of money will be spent because of the child's illness, disability, emotional or behavioural difficulties.
- As the carer of a child with additional needs you are also entitled to all the support anyone else would get in your position.
- A good starting place is your local authority's Local Offer which is an information service for parents caring for children with special educational needs or a disability
- An EHC needs assessment looks at whether a child needs an Education, Health and Care Plan. An EHC Plan is for children and young people aged up to 25 who need more support than is available through the existing special educational needs support everyone gets.
- If you need further information and guidance you can contact your local Information, Advice and Support Services (IASS). They are able to give free, accurate and impartial information to parents, carers and children and young people with special educational needs and disabilities.
- Parent Carer Forums (PCF) are groups of parents and carers of disabled children who work with all the people in the lives of children with disabilities and additional needs – like local authorities and h

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Useful organisations

Blue Badge Scheme

www.gov.uk/blue-badge-scheme-information-council

The Blue Badge scheme helps you park closer to your destination if you're disabled. It's named because of the badge you display in your window to demonstrate that you're part of the scheme.

Cinema Exhibitors Association Card

www.ceacard.co.uk

The CEA Card is a national card scheme developed by the Cinema Exhibitors' Association (CEA) for UK cinemas. It ensures cinemas make reasonable adjustments for guests with a disability and in particular ensures that these customers get a complimentary ticket for someone to go with them if required. You don't need to have a CEA Card for a reasonable adjustment to be made. If you require an adjustment to visit a cinema because of your disability the CEA's policy states that cinema staff should make it for you, so don't be afraid to ask.

Contact A Family

www.contact.org.uk

Helpline: 0808 808 3555

Contact a Family is a national charity for disabled children, providing information, advice and support services.

Council for Disabled Children

www.councilfordisabledchildren.org.uk

The umbrella body for the disabled children's sector bringing together professionals, policy makers and practitioners.

Disabled Persons Railcard

www.disabledpersons-railcard.co.uk

The Disabled Persons Railcard allows a person with a disability and their adult companions to get one third off most rail fares throughout Great Britain. It costs £20.00 for a one year and £54.00 for three years.

National Express Disabled Persons Coachcard

www.nationalexpress.com

The Coachcard entitles people with a disability up to a third off all standard fares throughout the UK. It costs £10 plus £2 p&p per year.

National Network of Parent Carer Forums

www.nnpfc.org.uk

Funded by central government, the Forum is made up of Parent Carer Forums from almost every local authority in England. It ensures good practice, knowledge and shared expertise about parent participation continues to grow and strengthen.



Nimbus Access Card

www.accesscard.org.uk

Tel: 01332 404040

The NIMBUS Card is a card that discreetly informs venues of people's needs. The individual needs of cardholders are assessed and entered into a secure database which then allows venues to access information on the barriers faced by the customer, including how they can support them.

Venues that support the card include Download Festival, All 02 Academies and even Glastonbury festival. The Access Card costs £15 for three years.

RADAR National Key Scheme

www.disabilityrightsuk.org

The National Key Scheme (often called the RADAR key scheme) provides people with a large silver-coloured key that opens more than 9,000 accessible toilets in the UK. It was developed because some public toilets designed for disabled people had to be locked to prevent damage and misuse. Having one key that unlocks all such toilets helps to keep them accessible to those that need them. Key cost around £5.00.

Scope

www.scope.org.uk

Helpline: 0808-800-3333

Scope provides advice and services for children and adults with learning disabilities or a physical impairment.

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