

Early Support

for children, young people and families

Information for living without a diagnosis



About this resource

In this resource you will find information on:

- why it can take time to get a diagnosis
- why parent carers want a diagnosis
- how you can access support for your child even without a diagnosis
- who can help
- tips and strategies
- where you can get further information and support

This resource is for parent carers who have young children with additional needs where no diagnosis has been made and there is no obvious cause for the symptoms a child has.

This resource was developed by **Contact a Family** for Early Support.

Early Support

Early Support is a way of working, underpinned by 10 principles that aim to improve the delivery of services for disabled children, young people and their families. It enables services to coordinate their activity better and provide families with a single point of contact and continuity through key working.

Early Support is a core partner supporting the implementation of the strategy detailed in Support and aspiration: A new approach to special educational needs and disability, the Government's 2011 Green Paper. This identified Early Support as a key approach to meeting the needs of disabled children, young people and their families.

Early Support helps local areas implement the Government's strategy to bring together the services families need into a single assessment and planning process covering education, health and care. Early Support provides a wide range of resources and training to support children, young people, families and service deliverers.

To find out more about **Early Support**, please visit www.ncb.org.uk/earllysupport.

Where a word or phrase appears in colour, **like this**, it means you can: look them up in the **Glossary** at the back of the resource; find contact details for the organisation or agency highlighted in the **Further information and useful links** section, or find out more in the **Who Can Help** section.

Explanation of the term parent carer

In this resource the term 'parent carer' is used. It means any person with parental responsibility for a child or young person with special educational needs or disability. It is

intended as an inclusive term that can cover foster carers, adoptive parents and other family members.

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Living without a diagnosis

There are some children who have learning impairments and/or health issues but no one can explain the cause.

Parent carers might first find out their child has an additional need when they are not developing at the same or equivalent rate as other children their age in areas such as muscle tone, sitting, communicating and playing with others. If a child has difficulty meeting one or more of these development milestones, this is known as developmental delay.

This can be a very worrying and difficult time for parent carers looking for answers and explanations. The term developmental delay can lead parent carers to expect their children to catch up with their development later. This will be true for some children but not for others and it might be impossible for doctors to know until the child is older or a diagnosis is made.

If doctors know the child will not catch up in their development they might use the term developmental impairment or disordered development instead of developmental delay.

Some families may be told that their child has **global developmental delay (GDD)**. This means that a child is significantly behind in at least two developmental areas or domains. These domains include motor skills, speech and language, cognitive skills, and social and emotional skills. The most common causes of GDD are problems with the child's **genes** or **chromosomes**. For some children, the cause of the GDD is never identified.

As the child gets a little older it might become easier for doctors to make a diagnosis; the child's additional needs become more obvious, making it easier to fit them with known syndromes. But some families live without a diagnosis for their child for many years and some never get a diagnosis for their child.

Genetic Alliance UK estimates that about half (50 per cent) of children with a learning impairment have no definite diagnosis.

It is natural to want to find a reason for the things your child finds challenging. This helps us to cope as we can understand what we may need to do to support our child, and helps us plan what to expect in the future. Without a clear diagnosis it can feel like you're in limbo, not knowing what's happening to your child or what the future holds. It can also feel frightening if you don't know how your child might progress.

As a parent carer, you may also worry that without a diagnosis or label for your child's impairments or additional needs, your child may not get the help and support they need. However, your child should get support based on their needs rather than their diagnosis.

See the **Getting the right support** section for more details.

“Having someone you can really talk to and who is not emotionally involved – such as a counsellor or health visitor – can be a great help, even if they don’t have all the answers.”

Parent

The causes of impairments and conditions

There are many reasons why children are born with impairments and/or health needs. These are often debated and can include:

- difficulties during pregnancy, such as infections the mother is affected by (for example Rubella)
- being born too early (**prematurity**)
- environmental problems, such as substances the baby is exposed to while the mother is pregnant (for example, alcohol or environmental pollutants, such as lead or pesticides)
- **genetic conditions**. Research has shown that these are more likely to occur when the parents are older or with inter-family marriages.
- **asphyxia** – a lack of oxygen or trauma, during or shortly after birth

In many cases, it is impossible for a doctor or **paediatrician** to say what caused your child's impairments or additional needs. If your child has a number of presenting needs they may not fit into any single condition.

Mothers may worry that it might be their fault that their child has additional support needs because of something they did while they were pregnant. However, it is rarely anyone's fault. In most cases, these things just happen and there is no way that the parent carers could have stopped it from happening.

“All the time you keep hoping that the doctors can say what is wrong and that there is something they can do. You want your child to suddenly catch up and be able to do all the things that other children do.” Parent

Why is it sometimes hard to get a diagnosis?

There are a number of reasons why getting a diagnosis is difficult:

- There are more than 6,000 rare conditions. Doctors rarely see, or read about, patients with these conditions, making it harder to recognise them in their patients.
- Different conditions can have similar features or symptoms, which makes it difficult for doctors to make a diagnosis.
- Some children have a number of features or symptoms that do not fit into one specific condition.
- There are significant differences in the way that one condition can affect different children, which can add to the problem of making a diagnosis.
- Certain things that indicate a condition may not appear until your child is older – this may result in a late diagnosis or even a change in diagnosis.

For many conditions the cause is not known, and even when children are in the care of the best medical experts a diagnosis is not made.

“Don’t compare your child to other children of the same age, or how your other children were at that age, as this can be upsetting. Every child is different.” Parent

What about advances in medicine?

Doctors are now able to diagnose more conditions than ever before, mainly because of advances in medical knowledge and improvements in testing techniques and medical equipment.

Testing, especially for **genetic conditions**, is improving all the time. It may be that a new test becomes available to determine the cause of your child’s impairments or other additional support needs. If it is suspected that the cause of your child’s presenting challenges or symptoms is due to a genetic condition, then you may be referred to a **genetics team**, which is based at your regional genetics centre. To get an appointment at your regional genetics centre ask your GP or paediatrician for a referral. In some cases referrals will be accepted from specialist nurses, midwives and non-genetic medical colleagues.

Specialists in clinical genetics (called **clinical geneticists**) can assess your child and order tests to try to identify the cause of their symptoms. The genetics team can offer **genetic counselling** and may be able to help to identify the risk of the genetic condition happening again in children you may have in the future.

If your child has an undiagnosed condition, you may have several appointments with the genetics team. The team may get in touch with you if there is the opportunity for you to try a new test for diagnosis. It may also regularly review your child’s presenting challenges or symptoms and help decide the best way to manage these, as well as referring to other

specialists who can help. The team may, for example, ask you to come back every one or two years for reassessment. If your child has not been reassessed in the past five years then do ask for a referral.

The improvements in science and medicine can lead parent carers to believe that practitioners can always find out why something has happened to your child. Sometimes this isn't the case and this can be disappointing for families.

New conditions are being identified all the time

Another factor that contributes to the difficulty of diagnosis is the large number of new conditions that are being identified. Parent carers who have been told previously that their child has a developmental impairment may be presented with a number of conditions suggested as possible diagnoses. This can raise hopes of a precise diagnosis, but it can still take some time to find the right specialist who is able to make a diagnosis.

Trying to get a diagnosis

Tests, assessments and medical appointments

Trying to get a diagnosis can mean your child having lots of different tests and assessments, and appointments with different specialists. This can be a worrying and anxious time for parent carers.

Repeatedly having to explain your child's medical problems to different practitioners can be disheartening. It can also be frustrating and upsetting when hopes are built up that a test or assessment may bring a diagnosis and it does not. It is quite natural to feel disappointed when practitioners don't have the answers you are looking for.

Managing information

It can be difficult to manage all the information from appointments. Some parent carers find it helps to get a diary or a big wall calendar with loads of space to mark appointment times down. Keeping paperwork is key – keep copies of all letters, appointments and test results in a folder. The Early Support [Our family](#) resource can help with co-ordinating support and sharing information. Find out more information here: www.ncb.org.uk/early-support/resources

Another top tip is to make sure you receive copies of all the letters sent by different specialists, to ensure you are kept up-to-date. Write on them after the appointment what was said and what is planned. It does help if you can take a family member or trusted friend to these appointments. There could be a lot to take in and they may well remember something said that you might have missed.

What to do if you are not happy

If you feel strongly that all avenues to getting a diagnosis have not been explored, you should discuss this with your **GP** and you may be able to request a second opinion. **Contact a Family** can also offer support and advice if you are unhappy with your child's care. However, sometimes everything that can be done has been done and you are still left with no diagnosis.

Why parent carers want a diagnosis

Feeling in control

Many parent carers say they want a diagnosis for their child as it helps them to feel in control of their situation. However, you can still support your child; see our [Getting the right support](#) section for more information. Parent carers say they feel more certain about their future if they know the name of their child's condition and how it may progress over time.

Lots of parent carers say they want to research their child's condition to find out how they can best support them. Without a diagnosis this search can be difficult. **It is worth remembering that even with a diagnosis the same condition can affect children in different ways**, so general information would still need to be discussed with your child's specialist to see if it applies. If your child doesn't have a diagnosis, specialists may not know how the child will be affected as they grow – often it is a case of 'wait and see'.

Future children

Knowing the name of the child's condition can also help with practical issues, such as planning to have more children. But you can still get an empirical risk (which is a best guess) of the chances of the condition affecting future children. This will be given by a [clinical geneticist](#) and takes into account lots of different information. If you haven't had a genetics appointment for your undiagnosed child for over a year and you're thinking of having another child, seek an appointment through your [paediatrician](#) or [GP](#).

"Try not to worry too much about the future. Try to focus instead on dealing with each day at a time." Parent

Communicating your child's needs

It is much more difficult explaining to family and friends what your child finds challenging when you have not got a name to put to it. However, even with a diagnosis parent carers often still have to explain how this affects their child.

It is also challenging when meeting practitioners to have to explain your concerns about your child, any symptoms and things they find difficult each time, rather than just being able to say my child has 'X' syndrome. This can be especially frustrating and tiring if you have a lot of appointments. However, you might have to do this even if your child has a diagnosis as the same medical condition can affect children in different ways, and levels of severity can vary.

To save having to constantly repeat your child's story, you can create a [communication passport](#) for your child. A communication passport is a booklet that is used to pass on crucial information about a child or young person, such as information about their condition, medications, likes and dislikes, and essential information should an emergency situation occur. [The Foundation for People with Learning Disabilities](#) has a good template

for a communication passport in their booklet *An ordinary life*. **Bristol Children's Hospital** produces a good hospital passport for children to use when they are admitted for treatment.

"I'm tired of having to explain to people that my child isn't naughty but has an unnamed condition." Parent

How important is getting a diagnosis?

While most parent carers say that they would like a diagnosis, over time they find that getting a 'name' is not as important as it had been at first. For most parent carers, the priority is ensuring that the day-to-day needs relating to their child's condition are met.

Many say that, even with a diagnosis, they would still have to explain what the diagnosis means, particularly to people who do not work in genetics or medicine. For many parent carers, getting a diagnosis is just something that would be nice to know.

"I felt that getting a name for our daughter's condition would help us when explaining to others what was wrong, but in the end it didn't really matter. All the professionals involved needed to know was what the immediate difficulties were, so the right care could be arranged." Parent

"For so many years, all I wanted were answers, a diagnosis – a name; to know what we were facing. Finally when Jamie was around 13 or 14 I suddenly stop seeking and worrying so much. I learnt to enjoy him for who he is and not be so obsessed with what was wrong with him." Parent

Getting the right support

A lot of parent carers fear that their child will not be able to get the support they need without a firm diagnosis. Not having a diagnosis may matter very much to you as a parent carer and it may matter to your child as they get older. However, for many practical purposes, it doesn't make any difference whether you have a diagnosis or not:

- Treatment, therapy or other support services should be tailored to your child's needs, not to the name of their condition.
- Strategies that you can use to help your child's mobility or speech and language development are suitable for many children with different conditions and impairments.
- You're entitled to have a **social services assessment** of your child's impairments and support needs and of your needs as a parent or carer, whether your child has a named diagnosis or not. You can request an assessment by contacting your social service department – in some places there may be a Children with Disabilities team that you can contact. Your GP, paediatrician or health visitor may also ask on your behalf.
- You're entitled to receive benefits, such as **Disability Living Allowance (DLA)**, on the basis of the difficulties that your child has and the support they need. Find out more about this in the Early Support resource [Background information: financial help](#). The **Contact a Family** helpline can also offer advice on benefit entitlement.
- Parent carers also worry that assessments and claims for financial support won't be taken seriously if their child is listed as 'undiagnosed'. Ask your specialist or **paediatrician** to write a letter to outline the presenting features or symptoms your child experiences and what effect this has on daily life to support your claims.
- Your child is entitled to have extra or different support to help them at their chosen nursery, preschool, other early years setting, or school if they need it. This does not depend on knowing the cause of their learning impairments. Contact a Family has information on special educational needs (SEN) and can give advice through their helpline as well. Early Support has a resource called [Background information: education](#), which contains further useful information.

Just because your child does not have a diagnosis, it does not mean that you are not entitled to support. Your child would be recognised as disabled because of their additional needs, which affect their day-to-day living. The legal protection that applies to disabled children would also apply to them – for example, the Equalities Act 2010.

Getting support for you

Having a child who has additional needs, but who doesn't have a diagnosis can be emotionally draining. It is important that as a parent carer you get as much support as possible. Useful support networks include extended family and friends. Early Support has a resource called [Looking after yourself as a parent](#), which explores ways to de-stress and build effective relationships with others.

Find out more information here: www.ncb.org.uk/early-support/resources.

You may find it helpful to set up a **circle of support**. This is a group of people who meet together on a regular basis to help someone accomplish their personal goals in life. The circle acts as a community around that person (the 'focus person') who, for one reason or another, is unable to achieve what they want in life on their own and decides to ask others for help. The focus person is in charge. They decide who to invite to be in the circle and how the direction the circle's energy is employed, although a facilitator is normally chosen from the circle to take care of the work required to keep it running.

It may be that your circle of support finds out about potential diagnostic tests, local services, or cultural forms of support so you don't have to do it on your own. The **Inclusive Solutions** website has good information about this.

"Raising a child with a disability can be hard work, both physically and emotionally. Don't be afraid to ask for help and take help when it is offered." Parent

Who can help

A **health visitor** can be a vital source of support for parent carers with children under five years. Many parent carers discuss their child's impairments or other additional support needs in the first instance with their health visitor. For other families, the first person they contact with concerns about their child may be their GP. Your GP may refer your child to a specialist children's doctor called a **paediatrician**. They in turn may contact specialist practitioners (also known as consultants).

If you feel that you need to see a specialist, or if you think you may have somehow got 'lost in the system', don't be afraid to phone to find out. Ask to speak to the doctor's secretary to find out what is happening with your child's appointment. Whenever you think of a question that you want to ask the specialist, write it down immediately so you don't forget it. A number of parent carers, for example, kept a notepad handy on their fridge, to jot down their questions.

Don't be afraid to ask your specialist the questions that are concerning you, however silly or insignificant you think they may seem. You may also find it helpful to take someone else with you to your appointments as a 'second pair of ears'. This person can take notes of the discussion you have with the specialist. Notes will be a great help later on when you try to remember what was said. If possible, try to stick with the same practitioners so you don't have to keep repeating your child's life story.

Your child may be assigned a **key worker** who provides advice and support, and can help negotiate the system. A key worker may be needed more at some times than at others. Families can decide what works best for them.

If you have English as an additional language you can get translation and interpretation support if you need this. You can also get signing and other communication support, so make sure that those who you are communicating with know of your communication requirements.

Supporting your child's development

Other health practitioners can be involved in helping your child to develop and reach their potential, such as **speech and language therapists**, **physiotherapists** and **occupational therapists**. If you would like to know more about what practitioners can do to support your child, look at the Early Support resource [Background information: people you may meet](#). Contact a Family produces a useful guide called *Concerned about your child*, which lists the practitioners who can help you if you have a concern about your child's development.

Your paediatrician may be your main point of contact and sometimes they can help you manage all the information coming in from various practitioners working with your child. See our **Top tips** section for practical advice on managing all the information you will receive about your child and their appointments.

You may find it helpful to keep a record of your child's progress. You can keep a diary, taking photos and videos if possible. As well as being a useful record to show to practitioners, it can also be comforting to look back and see the progress your child has made. You could also use the [Early Support Development journal](#) to record this information, which contains a set of charts so that families can record what their child is able to do.

Getting financial help/support

Parent carers often worry that when they fill out forms to get services or financial assistance, having no diagnosis for their child will work against them. You can ask your specialist or paediatrician to write a letter to outline the particular features and/or symptoms your child experiences and what effect this has on daily life to support your claims. Contact a Family's freephone helpline can offer advice on financial support to families, regardless of whether the child has a diagnosis.

Getting support for your child's education

Getting support for your child at nursery, preschool, other early years setting, or in school may be more difficult if you don't have a named condition. Teachers, early years staff, play care staff and classroom assistants may not understand your child's needs and may find it hard to research a condition if the child is undiagnosed.

Parent carers can improve the setting or school's understanding by getting a letter written by the child's specialist or paediatrician to list the child's needs and how best they can be supported.

A child with additional learning needs is entitled to get help in the setting/classroom based on their needs and not their diagnosis. The main point of contact for a parent carer whose child has [special educational needs \(SEN\)](#) is the early years setting or school's [special educational needs coordinator \(SENCO\)](#). If your child is struggling you may want to meet with your SENCO to see what support can be put in place.

You have the right to apply for your child to be assessed for a [statement of special educational needs](#). The statement will outline the support the child needs and the support the school must give them. This system will be changing in April 2014. To find out more about SEN call Contact a Family's freephone helpline or look at the Early Support resource [Background information: education](#).

There is also a [Parent Partnership Service \(PPS\)](#) in each local authority, which offers independent information, advice and support to parents and carers of children and young people and others with SEN or additional needs. [The National Parent Partnership Network](#) supports and promotes the work of PPS across England and offers support to parents and carers of children and young people with SEN.

"Try to enjoy your child. It is easy to focus on all their problems and forget to enjoy watching them grow up." Parent

Meeting other families

Parent carers often say what helped them most was meeting other parent carers who are in, or have gone through, a similar situation.

Local parent carer support groups

Many areas in England have a local parent carer support group where families of children with all kinds of additional needs come together for mutual support and contact. It might be helpful to find out if there's one near you. You can either call Contact a Family's freephone helpline, or contact your local [Family Information Service \(FIS\)](#) to find local group contact details.

A lot of the issues you face on a day-to-day basis will be familiar to other parent carers, even if their child has a different medical condition. Parent carers often provide information about support in their local area and offer practical advice on common problems. Groups can also provide a forum to share your child's achievements. Local groups have the advantage of meeting regularly and locally, which can be important in providing a wider support network if you need one.

National condition support groups

[Syndromes Without a Name \(SWAN\) UK](#) is a national network for families of children with undiagnosed genetic conditions. The group is run by [Genetic Alliance UK](#) and aims to build a community of families with undiagnosed genetic conditions.

Support groups and networks are often aware of research or studies taking place to find better ways of diagnosing certain conditions. As a family, you may consider taking part in studies, as these could offer new hope for a diagnosis. It is important to get as much information as possible so you can feel completely comfortable in taking part in any type of research. Each family will need to consider the pros and cons for them.

It is worth remembering that while your child may not have a named diagnosis, condition-specific support groups may have information you can use anyway. For example, [The National Autistic Society](#) may be able to offer useful resources for helping with behavioural problems, [I CAN](#) and [The Communication Trust](#) will have information on speech and language techniques, and [SCOPE](#) can provide solutions to the challenges of feeding and eating, and sitting.

"We visit a local group for families with children that have special needs, which is excellent." Parent

Top tips

Parent carers can find the number of practitioners and appointments they have to attend overwhelming when their child has no diagnosis. The following tips from parent carers who have 'been there' can help you to manage your diagnosis journey:

- Get a diary or a big wall calendar with loads of space to mark appointment times down.
- Make sure you receive copies of all the letters sent by different specialists to ensure you are kept up-to-date. Write on them after the appointment what was said and what is planned.
- Keep a paper trail. Keep copies of all letters, appointments, and test results in a folder. The Early Support [Our family](#) can help with co-ordinating support and sharing information, particularly when many different people or agencies are in contact with a child.
- Take a notebook to all your appointments so you can make a note of anything you think is important. If there is a word you don't understand, ask the medical professional to write it down for you so you can come back to it later or discuss it with other practitioners.
- Keep a record of your child's progress. Keep a diary, take photos and videos if possible. As well as being a useful record to show to doctors, it can also be comforting to look back and see the progress your child has made. You could use the Early Support *Development journal* to record this information.
- Create a communication passport for your child. This is a booklet that explains your child's health history, what your child can and cannot do, their medications and any other issues they have. It can also include your child and family's cultural identity and requirements. This passport can be taken to appointments and they are a quick and easy way of passing on information to the specialist about your child. Lots of hospitals now have hospital or communication passport templates.
- If you feel that you need to see a specialist, or if you think you may have somehow got 'lost in the system', don't be afraid to phone. Ask to speak to the doctor's secretary to find out what is happening with your child's appointment.
- Whenever you think of a question that you want to ask the specialist, write it down immediately so you don't forget it. A number of parents, for example, kept a notepad handy to jot down their questions.
- Don't be afraid to ask your specialist questions that are concerning you, however silly or insignificant you think they may seem.
- Take someone else with you to your appointments as a 'second pair of ears'. This person can take notes of the discussion you have with the specialist. Notes can be a great help later on when you try to remember what was said.
- If possible, try to stick with the same professionals so you don't have to keep repeating your child's life story.

Further information and useful links

Communication and hospital passports

Bristol Children's Hospital

The hospital has a good template for a hospital communication passport, which can be emailed before a child's appointment. It can also be used in other settings.

www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/bristol-royal-hospital-for-children/information-and-support/hospital-passport

0117 9230000

Include Me Too – All About ME

This alternative template by Include Me Too, can also be used in different settings and incorporates children's cultural identities and requirements alongside their impairment requirements.

www.includemetoo.org.uk

01902 3999888

Foundation for People with Learning Disabilities

The Foundation works to influence government and local authority policies and services so that they better meet the needs of people with learning disabilities, their families and carers. The Foundation's report *An ordinary life* has a good communication passport template.

www.learningdisabilities.org.uk/publications/an-ordinary-life-booklet

Circles of Support

Inclusive Solutions

A team of psychologists and associates who will work with anyone who wants to bring about the real changes in the system that are necessary to move towards a truly inclusive society. Its website aims to provide accessible, up-to-the-minute national and international information regarding training, books and cutting-edge strategies to support those on the front line of inclusive practice. See their useful information on a circle of friends.

www.inclusive-solutions.com/circlesoffriends.asp

inclusive.solutions@me.com

0115 9567305

Useful organisations

Contact a Family

This charity provides advice, support and information to families with disabled children in the UK, whatever the child's disability or additional need.

www.cafamily.org.uk

info@cafamily.org.uk

Freephone helpline:0808 8083555 (weekdays)

Early Support

It is a way of working, underpinned by 10 principles that aim to improve the delivery of services for children and young people with additional needs and their families. It enables services to coordinate their activity better and to provide families with a single point of contact, continuity of care and support through key working. Early Support ensures that service delivery is focussed on the child, young person and family, and that services and practitioners work in partnership with children, young people and their families.

www.ncb.org.uk/earlysupport

earlysupport@ncb.org.uk

020 78436350

Early Years Equality

Provides disability equality and other protected characteristic equality support, guidance, advice, discrimination casework and training to children, families, organisations, providers and policymakers across the UK.

www.eearlyyearesequality.org.uk

enquiries@earlyyearesequality.org.uk

0114 2700214

Genetic Alliance UK

This UK alliance is an umbrella body that represents many individual patient organisations. It runs several projects, including Syndromes Without a Name (SWAN) UK, and has lots of information on genetics testing and services, including a list of all UK genetics centres.

www.geneticalliance.org.uk

contactus@geneticalliance.org.uk

020 77043141

I CAN

Supports children with speech, language and communication difficulties. It offers a range of information services that provide help and advice to parents and practitioners about speech, language and communication.

www.ican.org.uk

info@ican.org.uk

0845 2254073

The National Autistic Society

NAS is the leading UK charity for people with autism (including Asperger's syndrome) and their families. It provides information, support and pioneering services, and campaigns for a better world for people with autism.

www.autism.org.uk

nas@nas.org.uk

Helpline: 0808 8004104

SCOPE

The charity supports disabled people and their families in the UK, providing help and information, services and campaigning. The charity specialises in helping people with cerebral palsy but will support any disability.

www.scope.org.uk

response@scope.org.uk

Freephone helpline: 0808 8003333

Syndromes Without a Name (SWAN) UK

SWAN UK is a project run by the Genetic Alliance UK, offering support and information to families of children with undiagnosed genetic conditions. It has an online community of families, a blog and a newsletter.

www.geneticalliance.org.uk/projects/swan

SWAN@geneticalliance.org.uk

020 77043141

The Communication Trust

The Communication Trust is a coalition of nearly 50 voluntary and community organisations with expertise in speech, language and communication. They harness their collective expertise to support the children's workforce and commissioners to support the communication needs of all children and young people, particularly those with SLCN.

www.thecommunicationtrust.org.uk

enquiries@thecommunicationtrust.org.uk

020 7843 2526

Glossary

Additional support needs – In this, and other Early Support resources, additional support needs is used to refer to any child or young person who has a condition or special educational need, whether diagnosed or not, who is likely to need additional support beyond universal services.

Asphyxia – A condition where there is a lack of oxygen in the blood and a build up of carbon dioxide, usually due to stopping breathing or suffocation.

Chromosome – A rod-like structure present in the nucleus of all cells in the body (with the exception of the red blood cells), which stores genetic information. Chromosomes are made up of tightly wrapped DNA containing our body's blueprint.

Clinical geneticist – A practitioner trained in genetics and skilled at providing advice about genetic conditions. Geneticists will be able to explain the results of any tests or examinations that you have and how to best manage and treat your condition. They may be able to give an estimation of risk of a genetic condition occurring in future pregnancies.

Circle of support – A group of people who meet together on a regular basis to help a person, known as the 'focus person', accomplish their personal goals in life. The members of the circle of support may include family, friends and other community members. They are involved because they care enough about the focus person to give their time and energy to help them.

Communication or hospital passport – A booklet that is used to pass on crucial information about a child or young person with additional needs. It contains information about a person's condition, medication, likes and dislikes, and essential information for an emergency situation.

Disability living allowance (DLA) – The main benefit for children and adults with a condition or impairment. It helps to meet the extra costs that you might have as a result of your child's impairments. It is made up of two parts: a care component and a mobility component.

Equality named coordinator/equality coordinator (ENCO) – A member of staff at an early years setting, out-of-school service or school, who has responsibility for coordinating equality provision.

Early Support Development journal – This journal can be used by families where children have impairments, additional needs or undiagnosed conditions. At the heart of the journal is a set of charts that families use to record what their child is able to do as time passes and they learn new things.

Family information service (FIS) – Provides a range of information on all services available to parent carers to help support their child up to their 25th birthday if they have additional

needs. It also hold up-to-date details of local childcare and early years' provision in your area.

GP – This is your family doctor, the first person to ask for medical help and advice. They can ask for your child to be seen by another specialist.

Genes – The basic physical and functional unit of inheritance. Genes, which are made up of DNA, act as instructions to make molecules, called proteins, which make up our bodies.

Genetic condition – A genetic condition is caused by changes (mutations) in genes (our body's blueprint), or chromosomes (the structures that DNA is strung onto). Genetic conditions will affect a person from birth. Some genetic conditions are passed down from the parents' genes, but others are always or almost always caused by new changes to DNA and chromosomes.

Genetic counselling – Can help a person or family understand their risk of developing a genetic (inherited) condition, such as cystic fibrosis or cancer. It can also educate them about the condition and assess the risk of it being passed on to any future children. It is not the same as psychological counselling or therapy.

Genetics Centres – There are 32 NHS genetics centres in the UK. These are organised on a regional basis and include both clinics, where you may see a clinical geneticist or a genetics counsellor, and laboratory services, where tests are carried out. Genetics services may have other professionals based within them. The service will support anybody that is affected by a genetic condition or is suspected to have a genetic condition.

Global developmental delay – A child may be described as having global developmental delay (GDD) if they have not reached two or more milestones in all areas of development (called developmental domains). These areas are:

- motor skills – gross motor skills (sitting up or rolling over) and fine motor skills, (picking up small objects)
- speech and language – babbling, imitating speech and identifying sounds
- cognitive skills – the ability to learn new things, process information, organise thoughts
- social and emotional skills – interacting with others and development of personal traits and feelings

Health visitor – A nurse who has undertaken extra training to work with families in the community where the child is up to five years of age. They can give practical advice on day-to-day matters, such as feeding, sleep, teething, development and behaviour. Some health visitors have specialist roles, such as involvement with children with impairments.

Key worker – Some families will be seen by a key worker regularly to make sure they have all the information they need. The key worker will also make sure that services from all the different areas, including health, education and social services, are well coordinated. Key

workers can act as a central point of contact for professionals working with families. They will make sure information about your child is shared where necessary.

Occupational therapist – An occupational therapist pays particular attention to hand and eye coordination, perception and manipulative skills. They can advise and provide suitable aids for feeding, dressing, toileting, bathing and play in younger children, and writing skills in older children.

Paediatrician – A practitioner who specialises in looking after babies, children and young people. A paediatrician can coordinate and liaise with other agencies involved in the management, care and education of the child and family.

Parent partnership service (PPS) – A statutory service offering information advice and support to parent carers of children and young people and others with SEN and other additional needs. PPS has a role in making sure that parent carers views are heard and understood and that these views inform local policy and practice.

Physiotherapists – Helps in the management and development of movement skills. There are a number of ways in which children can be helped. These may include exercises to strengthen weak muscles and games to improve coordination and motor skills.

Prematurity – The definition of a 'premature' or 'preterm' baby is one that is born after 24 and before 37 full weeks after the first day of the mother's last period. There are different levels of prematurity and these carry their own risks.

Psychiatrist – A practitioner who specialises in problems that affect the ways a person thinks, feels or behaves. A child and adolescent psychiatrist specialises in working with children and young people. The psychiatrist might want to meet the whole family before deciding what help is appropriate. They can prescribe medication and might suggest a child be seen by a clinical psychologist.

Social services assessment – A social services assessment is the process that social services uses to gather information about a child or family so they can make a decision about what help they need. Usually an initial assessment will take place with a further, more detailed, assessment taking place later on. The process for carrying out an assessment is contained within the Assessment Framework, which is statutory guidance that the local authority must follow.

Special educational needs (SEN) – Children with special educational needs have a considerably greater challenge in learning than others the same age. SEN includes communication, physical, sensory and emotional difficulties that require additional support to help a child reach their full potential.

Special educational needs coordinator (SENCO) – A member of staff at a school or in an early year's settings who has responsibility for coordinating SEN provision.

Speech and language therapist – A speech and language therapist helps children learn to communicate, either through speech or other methods. They can also help if there are challenges with eating, drinking and swallowing.

Statement of special educational needs – This is a document that records your child's impairment or other additional needs and the help your early years setting, playcare or school must put in place to meet those needs. You can request an assessment of your child's needs, which may result in a statement that is legally enforceable.

Syndrome – The association of several clinically recognisable features, signs (observed by someone other than the patient), symptoms (reported by the patient), phenomena or characteristics that often occur together.

Early Support

for children, young people and families

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contact a family
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