

Early Support

Helping every child succeed

Information for parents

Multi-sensory impairment



About this publication

This is a guide for parents with young children who have recently been told that their child has multi-sensory impairment, or who are in the process of getting a diagnosis. Multi-sensory impairment (or MSI) means that a child has problems with both sight and hearing.

This fourth edition was developed by the **Early Support** programme in partnership with **Sense**, in response to requests from families, professional agencies and voluntary organisations for better standard information. Families were consulted about the content and the text reflects what parents who have 'been there before' say they would have liked to have known in the early days of finding out about their child's situation. The current edition has been revised by **Sense** in the light of feedback from families and in response to changes in policy and practice that have taken place since the first edition in 2004.

The information is free-standing. However, some people may use it alongside another **Early Support** publications, such as the **Monitoring protocol for deaf babies and children** or the developmental journals. The Monitoring protocol/developmental journals help parents and carers track and understand a child's development, celebrate achievement and find out what they can do to encourage their child to learn.

To find out more about the **Early Support** programme and associated training or to view or download other materials produced by the programme, visit <http://www.dcsf.gov.uk/everychildmatters/earlysupport>

Where words are printed in colour and italics, *like this* it means that a parent said it.

Where a word or phrase appears in colour, *like this*, it means either that it is a technical term that is explained in the text around it, or that you can find out more in the **Who can help?** section.

If the name of an organisation appears in colour, it means that you can find their contact details at the back of the book.



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Introduction

The birth of a child is a major cause for celebration in any family, bringing with it the kind of joy and happiness that cannot be compared with anything else. It brings a change in family life, with an increased sense of responsibility for the newest and most vulnerable member of the family.

The birth of a child with disabilities gives rise to even more emotion. At this time of high expectation, feelings of joy at having a new baby are mixed with uncertainty and, sometimes, fear for the future. This is a particularly stressful time for families, who cannot know what to expect for their child. It's like entering a new world.

This booklet gives information you may find helpful in this new world. It is written for parents of babies and young children with multi-sensory impairment, or MSI. MSI is the term used when a child has problems with both sight and hearing.

When babies have complex needs, it is sometimes hard to know how well they will be able to use their sight or hearing as they grow and learn. You may find this booklet helpful if there are doubts about your child's sight and hearing.

The booklet gives information about:

- what MSI may mean for your child and for you
- the support available for your child and family
- tips for helping your child to communicate and develop
- where to find out more.

Other parents of children with MSI have suggested what should be included here, but you may well find some parts of the booklet more helpful than others. Remember, every family is different. Use it in whatever way suits you best.

In the beginning

'It was a planned pregnancy that went very badly from the start. The fact that we ended up with a child at all was completely amazing.'

Multi-sensory impairment (MSI) arises from a wide range of causes. Children may be born with MSI or acquire it following illness or injury. In either case, in the early days, it's often difficult for doctors to make a diagnosis and for other professionals to get a clear picture of the child's abilities and needs. This can be very hard to come to terms with.

'For the first three or four months our son was constantly in and out of hospital and we were never at home for longer than two weeks at a time. We knew that he had lots of problems but there were still lots of unknowns.'

Many children with MSI need treatment in hospital early in life. As a result, parents may not be able to hold and cuddle their baby much, or to care for the child themselves, because of their treatment. It may seem that the 'system' has taken control and that other people - professionals - are the only ones who know how to care for your baby. This is not true.

Always remember that you, as parents, are the most important and knowledgeable people in relation to your child, and you are the people that your baby needs most.

Feelings

'I remember in the early hours after his birth feeling that if I could make the choice between no child or one with difficulties then I was ready to receive that tiny bundle and follow the very unexpected path ahead.'

When parents find that they have a baby with MSI, it's a natural reaction to feel distress and a sense of loss. Emotions run high - you may feel shocked, disbelieving, angry and helpless. It's not uncommon for friends and family to find it difficult to know what to say. These reactions are hard to bear, but normal. It's important to remember that there's no 'right way' to feel and that your feelings will change over time.



'There was no time to come to terms with any disabilities as just getting to and from the neonatal unit for three months whilst trying to start our older child in reception class was as much as I could manage.'

It's not uncommon for parents to feel lonely and isolated. You, and other family members, may feel overwhelmed by lack of experience of having a child with special needs. You may not know anyone else in the same situation and so may not be able to share experiences. MSI is so rare that even medical staff may have met few other children with similar needs and may not be able to answer all your questions with the certainty that you would like.

Sometimes a baby will have none of the complications at birth that signal sensory impairment, but over time families begin to suspect that something is affecting their baby's development. Families in this situation often face their biggest worries in the early days alone, without emotional support or information, until they get a diagnosis.

This is a time of very high emotion. Other families say that getting back to doing some ordinary, everyday things with family and friends can give you a bit of time and space to enjoy and get to know your new baby.

'Somewhere along the way, I started to change my whole mindset about our son's disabilities - I don't compare him to able-bodied children and am excited by the small steps of progress he makes. Although it's hard work caring for a disabled child, our son gives me so much pleasure.'

Early relationships and bonding

The bond between baby and parents usually begins from birth, and all the handling and care that babies need helps to make a relationship. Eye contact, smiling and gurgling all help to build the bond between you and your child.

For children with MSI, this initial 'getting to know you' time may be interrupted by the baby's medical needs. The normal early contact between parent and child may not take place and, as a result, it may feel more difficult to develop a bond with your baby. Building a relationship is naturally more difficult when a child has impaired vision and hearing.

This is because babies usually begin to develop relationships by making eye contact and by hearing their own voice, or other people's voices. Just knowing this can help you to find other ways to make a connection to start the relationship developing.

Looking after yourself

Remember your own needs. This can be hard to do, when your baby needs so much help, but it's important to avoid becoming completely exhausted.

'Having close friends and family around me, and feeling able to discuss things openly with them, helped a lot.'

- Most people want to help, but may not know how. Accept offers of help from others, and tell them what you need - your shopping done, other children collected from school etc.
- Try to take some breaks. Plan time to have a bath, read a magazine or have a nap, then make sure you do what you've planned.
- Go out by yourself or with your partner or friends. This may be difficult to arrange, but it will give you a chance to get away and recharge your batteries.
- Don't ask too much of yourself. Recognise that this is a difficult time, and that you can't carry on as normal. Work out what you really have to do, and leave the rest.
- Try to take one day at a time.
- Talk to people if you want to. If you feel that family or friends don't understand, talk to the doctors or other professionals you meet, or contact a voluntary organisation such as Sense.

Remember that professionals are there to help you, not just your baby.



You may also find it helpful to talk to other parents in a similar situation. There's more information about how voluntary organisations can help put you in touch with other families later on.

This booklet suggests places to look for help and support and passes on some tips based on what other parents with children with MSI say worked for them, as they tried to build a closer relationship with their child.

Wherever the name of a professional is presented in colour, [like this](#), you can read more about what they do later in the booklet.

What is MSI?

How we use our senses

Our experience of the world, our 'reality', comes through our senses. People with hearing and/or visual impairments, for this reason, have a different 'reality'. They don't experience the world in the same way as sighted hearing people; their whole knowledge and experience of the world is different.

Sight and hearing are often called the **distance senses** because they give us information about what's happening around us. Touch, taste and the balance senses are **close senses**, giving information only about what is happening now, within arm's reach. Smell gives some distance information, but it's much less useful to us than sight and hearing. Sight and hearing provide most of the information we need to learn and function.

Very young babies mainly use touch, taste and smell, but even from birth they get some information from sight and hearing. Over time, they develop visual and auditory skills that enable them to get better-quality information and use it better.

When one distance sense is impaired, information from the other can be used to compensate to some degree - for example, a deaf person lip-reading. People with single sensory impairments can also use their undamaged sense to keep in contact with the world around them. Children with MSI, however, cannot use either of the distance senses to compensate. In addition, many children with MSI have impairments of other senses, as well as sight and hearing. They may have poor balance, limited movement, under-sensitive or over-sensitive touch or an impaired sense of smell.

Children with multi-sensory impairment need to get as much information as possible from their residual sight and hearing and from their other senses. For many children, touch can provide a means of learning about the world and a means of communicating. Some children with MSI become very skilled in using the sense of smell, for example, and use it to identify people. Some recognise movement around them because of something as subtle as changes in air pressure on their skin.



Multi-sensory impairment

Children with multi-sensory impairment have impairments of both sight and hearing. Many children also face other challenges, such as medical conditions or physical disabilities.

A very small number of children with MSI are totally blind and deaf, but most have some useful vision and/or hearing. It may not be clear at first how well a child will be able to see or hear, especially if they have other problems.

Multi-sensory impairment is a very rare disability, particularly in children. There are an estimated 4,200 children with MSI in the United Kingdom (about 3 in every 10,000 children).

A huge range of conditions can cause multi-sensory impairment. There's no single or main cause. Diagnosis can take months or even years, and sometimes no specific cause can be identified. Many parents find this very difficult, especially not knowing how their child's condition might progress in the future.

Many of the conditions causing MSI are extremely rare. Local medical staff may have little experience or knowledge of your child's particular diagnosis. More information may be available from [Sense](#) or [Contact a Family](#). Every child has different, individual needs, and children with the same diagnosis vary enormously in their abilities and character.

Some causes of MSI may also affect other family members. If this is the case for you, you may be referred to a genetic specialist to learn more.

Some conditions may cause changes over time, in how well children see or hear, or in their health or general development. Some conditions causing MSI also limit life expectancy.

Some children acquire MSI after an illness or injury. Their families may be caught between joy at their child's survival and grief at the changes in their child's abilities and their hopes for the future.

Professionals working with the families of children with MSI will be able to provide help and support, directly or by referring to other specialists. Voluntary organisations can also offer support and contact with other families who have experienced similar changes. It is a new world, and a very different one, but you are not alone in it.

What does MSI mean for my child?

We normally get most of our information about the world around us through sight and hearing, so multi-sensory impairment makes a significant difference to children's learning and development.

Without extra help, MSI effectively restricts experience to the here-and-now - what is happening at this moment, within arm's reach. Children may not realise that the wider world exists, or they may find it so

confusing and threatening that they ignore it as far as possible. Most children with MSI need extra help with the following areas:

- Children with MSI are acutely deprived of sensory information. Touch, taste, smell, balance, awareness of pressure, temperature and pain may be affected as well as sight and hearing. Children with MSI may be very slow to learn to use their residual senses, because it's much harder to learn to understand and use sensory information that is partial or distorted.
- Relationships with others often take a longer time to develop, but children with MSI do develop close relationships, especially with their family, like any other child. Initially, children with MSI may seem unresponsive to parents or carers, because they don't see or hear the smiles, looks and speech most babies respond to. They may also sometimes seem to be unwilling to be held, especially if they have needed a lot of medical treatment, but they will tune in as contact increases.
- Children with MSI often take longer to realise that their actions affect what happens to them. This means that they are slower to learn to communicate. As they develop, they may use objects, gestures, signs or pictures to help them understand and make their wishes known.
- Seeing their surroundings plays an important part in motivating most children to learn to move independently. Sight also motivates children to learn to use their hands. This is very important for children with MSI, who generally need to use their hands much more in exploring, learning and communicating than sighted hearing children do.
- Learning to explore their surroundings helps children to understand and learn to control them. MSI reduces children's ability to anticipate events - to know what is likely to happen next - and this makes exploration harder. Children with MSI often have problems generalising skills and knowledge from one situation to another, because they don't see the similarities and differences between different situations.



- Children with MSI cannot learn by watching what happens around them, as sighted hearing children do. MSI makes children learn more slowly, because they get information that is of poorer quality. This does not mean that they necessarily have cognitive learning difficulties. Learning through touch is much slower than learning through sight, and understanding visual or auditory information takes more time when you have a sight or hearing impairment. Nevertheless, children with MSI can and do learn effectively.

These are the big challenges that children with MSI face. With the right support, however, they can learn to make best use of their sight, hearing and other senses, and develop the confidence to be inquisitive and interested in the world around.

Being together

'When our son was born I didn't know about bonding, I believed the priority was food and medication, followed by achieving all the therapy targets given to us. Feeding was so difficult and the targets so numerous that there was no time just to sit holding him and for us to learn to enjoy being together.'

Building relationships

Families are the most knowledgeable people about their children, and are their children's best source of nurturing and learning. Although some children with MSI may not react in the usual way to close contact with others, they are almost certainly aware of it and comforted by it. They will develop close relationships with parents and other family members.

Here are some tips that may help:

- Children with multi-sensory impairment may only be aware of other people when they are very close to them. Try to stay close to your child as much as possible, so that they can pick up information about you through smell, touch and warmth, as well as sight and hearing.
- Spend time holding them closely, echoing any small movements with your own. In this way you will be alert to personal signals from them (changes in breathing pattern, for example), and be able to respond in a way that they can pick up.
- Make sure the different people who care for your child have particular ways of identifying themselves - for example, a bracelet they always wear and which they show to the child, or a particular song or gesture they always use in greeting. This allows your child to begin to recognise the different family members and professionals they meet and to feel more relaxed. It can also help other people understand how to begin their meeting with your child - they may be very nervous of doing the wrong thing. If they start their 'Hello' with your child in this way, they can also develop a similar way of saying 'I'm going now' before they move away.
- You may have pets in the house. They are also part of the family. They need to be introduced to your child carefully and you may need to take additional care to make sure the contact is fun.



Understanding your child's behaviour

A very important part of caring for babies or children with MSI is learning to understand their behaviour. This means watching them closely and trying to interpret very small changes in what they do. It also means remembering that children with MSI experience the world very differently, and may therefore behave in ways which seem unpredictable or different.

Having limited sight and vision can make the world around seem hostile, noisy and confusing. Each child will respond differently but some may become self-protective.

Recognising what your child finds difficult will help you to make the world more manageable for them - for example, by limiting the time spent shopping in busy, noisy places.

Using limited sight and hearing, or operating without sight or hearing, is also tiring and often frustrating. Children may need frequent breaks from looking, listening, exploring or communicating. Conventional play activities may well be demanding rather than relaxing for a child with MSI, so they will need to relax in their own way. However, children with MSI do enjoy the same kinds of visits to theme parks and adventure playgrounds as their brothers and sisters and sometimes have more fun on the Big Dipper than their parents!

Interacting and communicating

Many parents say that in the very early days their child seemed not to respond to them, and that they found this very difficult. Babies and children with MSI do respond and do communicate, as all children do, but it may be harder for families to read the signals they give at first. Sighted hearing babies use eye contact, smiles and babbling, and we automatically look for these responses.

Babies with MSI sometimes respond by moving their arms or legs, rather than by changing their facial expression. If they're listening intently to a familiar voice, they may become very still. It can take time to recognise and learn these individual responses.

Sighted, hearing babies gradually learn that their sounds and actions affect what happens to them. Once they know this, they begin to try to communicate deliberately - for example, by trying to get attention.

Children with MSI get less feedback about the effect of their actions and so may take longer to learn to try to communicate.

You may find the following tips useful in helping your child to communicate:

- Most young children love very simple action games and songs, like 'Peekaboo' and 'Round and round the garden', especially if these are repeated again and again (and again!) Children with MSI may need lots of repetition before they are likely to show that they recognise the rhyme. Once they do, however, they usually love sharing the game with you. You may develop a set of favourite rhymes that are special for you and your child.
- We often copy a baby's behaviour - repeating a sound they have made, for example. Doing the same with a child with MSI, even when they are older, helps them to realise that what they do affects what you do in response.
- Children with MSI often take much longer to respond to something they have seen or heard. Although it can feel strange at first to wait and wait for a response, it gives your child the chance to take their turn in the conversation.
- **Object cues**, or **objects of reference**, can be used to help children know what's about to happen, because they miss most of the signals available to sighted hearing children. Before lifting your child into their high chair, for example, you might give them their feeder cup and wait a minute or so for them to take in the information. At first your child will not understand what the cup means. Then they will come to learn that it means something different is about to happen, and eventually that it's time for a drink or snack. You may find other ways of telling your child about changes - different songs for different activities, perhaps, for a child who loves music. Whatever you choose, it needs to be used as consistently as possible to allow your child to make sense of it.
- If you have clear, consistent routines for daily activities, it's easier for your child to learn to anticipate what will happen next and, eventually, to show you whether or not they want it to happen.
- Wherever possible, allow your child to take the lead and to control what's happening. If children with MSI feel that they cannot affect what happens to them, they may give up trying, and so stop learning.



- Children with MSI may respond to signals that sighted, hearing adults are not even aware of - for example, the draught from an open door. If you notice this happening, follow it up, so the significance of the information can be explained to your child by linking it to something recognisable. In supporting your child in this way, you'll begin to tune in to some of their characteristic ways of behaving and start to interpret what they're doing. You'll soon begin to pick up the more intentional signs that indicate, for example, that your child is ready to move on to another activity, or when they want to repeat what they have just done.
- The most important thing about communicating with children with MSI is to follow your child's lead and to respond to any signals they give. Even if you're not sure what they mean, make the best guess you can and react. The more your child realises that other people respond to what they do, the more motivated and skilled they will become as communicators.

Some children with MSI communicate by body movements, facial expression, sound or by pushing or pulling an adult towards something they want. As time goes by, some children begin to use more formal communication systems, which allow them to refer to things beyond the here-and-now.

The systems which can be used include:

- **objects of reference** - over time children may learn to use smaller objects, or parts of objects, to make the items less bulky
- gestures - often taken from the actions used during an activity
- symbols, pictures or photos
- tactile symbols
- signs, usually from **Makaton** or **British Sign Language**
- fingerspelling, where each letter has a particular handshape
- speech.

A child may use more than one system. Many children use one approach for receptive communication ('listening') and another for expressive communication ('talking'). Anyone who works with you and your child who has specialist knowledge of MSI should be able to discuss different communication options with you.

Playing and learning

Making sense of the world

Children with MSI get very little information from the world around them, and the information they do receive is often inconsistent and distorted. So events need to happen very consistently if children are to make any sense of what they are experiencing. Some children will go on later to develop the use of speech or signing or other communication modes, but they all need help to anticipate what will happen next in the early days.

Parents or carers can help to make the world more understandable in the following ways:

- Learn how to tell your child what's happening, and what's going to happen, in a way they can understand. Cues (such as an armband for swimming, or a particular song sung every time you're going out in the car) can be used to mark the beginnings and ends of events and to help identify activities. Objects used in this way to refer to a person or an activity are called **object cues** or **objects of reference**.
- Develop set routines - for example, dressing your child, getting ready for dinner or saying goodbye in the same way every time you do it. Be as consistent as possible, using the same place, the same person and the same object to signal that something familiar is happening or is about to happen. With family life, this can be difficult (or even impossible at times) but consistent presentation will help your child recognise and understand what is happening.
- Try to lay out the physical environment in the same way all the time, with furniture always in the same place. This promotes mobility, giving young children the opportunity to learn, while exploring safely. This also has an impact on other members of the family, however, and brothers and sisters have their own games to play!
- Encourage your child to participate by touching, smelling or tasting. Hold their hands over yours while you make a drink, mix paint or put the toothpaste on the toothbrush. It is not unusual for children with MSI to explore objects using their feet, and so shoes and socks may come off. It takes longer, if you encourage your child to participate like this, but it gives them a chance to understand what's happening better.
- Take time. This is important. Children with MSI get so little information that they can't afford to lose any more. Once you've established a routine, it's important for your child to recognise each different part of the activity. It can be difficult to maintain this, but if you can allow extra time for everyday activities, it will pay dividends.



Using limited residual vision or hearing is tiring. Using touch for information is incredibly slow compared to using sight. Children with MSI therefore take much longer to understand and respond to information. Explain this to other people, using examples that help them to put themselves in your child's place. For example, ask them to imagine half-hearing a remark someone has made, then realising what they have said a moment later, or trying to find a torch by touch during a power cut.

Playing

Sighted hearing children develop through playing, learning and practising new skills and understanding. They repeat actions that have interesting results and gradually learn to plan an action to achieve a particular end. They learn to imitate and to use more and more different objects. They begin to play imaginatively. And they play with adults from the very beginning, developing relationships and learning to communicate.

Children with MSI need extra help through all these stages. Some children find exploring exciting, while others seem unwilling or unable to explore and interact with other people through sight, hearing or touch. Here are some ideas that may help:

- Try to go at your child's pace. They may need to repeat actions many, many times, especially if they are using touch rather than sight.
- Make sure your child is as comfortably positioned and as relaxed as possible.
- Watch them playing to find out what interests them most. For example, they may prefer to explore objects using their mouth or feet rather than their hands. If your child has very repetitive behaviours (such as tapping everything against their face), try to find different playthings that give them a range of different experiences when they use this behaviour.
- Develop turn-taking games - for example, action rhymes, cradling, and rocking and bouncing games. These provide opportunities for stimulating the use of vision (for example, making eye contact), use of hearing (for example, by singing close to the child's ear) and for increasing tolerance of touch. An ideal time for these types of games is after a bath, when a massage session could also be incorporated.

- Offer opportunities for your child to play with food. Children who develop normally have lots of opportunities to experiment and play with their food and this leads to interacting with other substances like paint, playdough and clay. Children with MSI may always be fed by an adult and some opportunities may be lost. Playing with food substances like yoghurt or custard allows children to explore using vision, touch, smell and taste at their own pace and away from the pressure of mealtimes. It can help children learn about the properties of different substances and how substances change.
- Choose toys that suit your child's needs. Specialist equipment and toys designed to meet the needs of children with MSI are available (for example, bubble tubes and fibre optic cables) and you'll see these in schools and nurseries. But playthings don't need to cost a lot of money - everyday objects may be better than toys, as long as you check for safety. Children find ordinary items lots of fun to look at and play with - for example:
 - different types of brushes
 - torches, preferably with different coloured lights
 - a washing-up bowl half-filled with warm water
 - shiny silver paper and unbreakable mirrors
 - material with different textures, like paper, bubble wrap, sponge and fur
 - rattles made from small containers filled with rice or dried beans.

Some children also enjoy 'helping' in the kitchen. This could include:

- unloading washing from the washing machine into a basket
- mixing sandwich fillings (and licking the bowl)
- unpacking shopping bags
- sweeping with a dustpan and brush
- putting things in and out of egg boxes or clear yoghurt cartons.



Developing the senses

Most children with MSI have some useful sight and/or hearing, but they need help to learn to make the best possible use of these and their other senses.

MSI can affect how children use their senses in a number of ways:

- Children may be unable to use more than one sense at a time. For example, they may be able to look or listen, but not to do both at once.
- There may be a long delay before a child responds to something they have seen, heard, touched or smelled.
- Some children have fluctuating (varying) levels of sight and/or hearing, so one day they may see an object or hear a sound, but the next day they won't. This can be confusing and frustrating, and it often leads other people to make false assumptions about what the child is or is not capable of doing.
- Some children are unwilling to touch or be touched. This is sometimes called **tactile defensiveness**. **Tactile sensitivity** means children are unwilling to touch particular textures.
- Many are very slow to learn the skills associated with seeing and hearing - for example, watching an object as it moves. This is partly because a hearing impairment makes it harder to learn visual skills and vice versa.

Children with MSI often seem to make better use of their remaining sight and/or hearing as they develop knowledge and confidence about the world around them. In the early days, they may find it hard to identify what they see or hear, and sights and sounds may be so confusing that the child can't begin to make sense of them.

The following tips may help you to help your baby make best use of their remaining senses.

- Play, talk or sing with your child held very close to you - for example, on your lap. This is an excellent way to help children make sense of what they see and hear. Your voice and appearance will give good-quality information, because you're so near to your child's ears and eyes. Distracting, irrelevant background sights or sounds will be partly blocked out by your closeness. Being close will also help your child to feel secure, and give them extra information through touch, smell and the warmth of your body.
- Cut down the number of sights and sounds competing for your child's attention. If you're playing and singing with your child, turn off the radio and the TV. If you're looking at a toy together, try not to have too many other objects near it.
- Encourage young children to explore your face. If your child wants to do this, let them feel your breath and show them how your mouth moves and your throat vibrates when you talk. Some children may also like to feel your jaw move as you chew - this helps them understand more about the process of eating.

Spectacles and hearing aids

Whether or not spectacles and/or hearing aids are prescribed will depend on what kind of sight and hearing impairments your child has, and how severe these are. We are used to the idea that glasses make vision perfect and hearing aids restore full hearing. For children with multi-sensory impairment, aids for eyes or ears will almost certainly help their levels of sight or hearing if they are prescribed. However, even wearing their aids, they may still not see or hear as well as other people. Ask whoever prescribes the glasses or hearing aids how much they're likely to help.

A child needs time to get used to glasses and hearing aids - both to the feel of the aids on their face, and the difference the aids make to levels of sight and hearing. Your child may need to wear the aids for very short periods to start with (initially perhaps a few seconds). Talk to your [teacher of children with MSI](#) or [teacher of the deaf](#) about how to build up tolerance. Hearing aids, in particular, may be more useful in some situations than others - most hearing aids make all sounds louder, so when there's a lot of background noise (for example, on a busy road) they may not be helpful. If you understand how hearing aids work, you'll be able to help your child to use them better.



If your child suddenly rejects their glasses or hearing aids, check whether:

- the aids fit well, are working and clean
- whether the surroundings are unusually noisy, bright or it is otherwise difficult to hear or see
- your child has an ear infection, an eye infection or another health problem, or whether they're just tired and generally fed up
- your child is comfortably positioned and interested in what's going on.

Be confident about listening to your instincts and to what your child is trying to tell you. If you can't work out why they're rejecting hearing aids or glasses that they've previously worn, you may want to ask for their hearing or sight to be checked again, in case something has changed.

Daily living

Everyday life

Children with MSI are affected by their surroundings and the behaviour of people around them, just like everyone else. Exploring the environment is more tiring and more stressful for these children than for sighted hearing people, so they're more affected by conditions such as hunger, tiredness or pain, and by cluttered, noisy or unfamiliar surroundings. Knowing the things that affect your child the most will help you decide what you might change in your surroundings or in the behaviour of people working with you.

There may be some types of behaviour that concern you, including very demanding or repetitive behaviour. You may want to seek advice about these from a specialist practitioner, such as a [teacher of children with MSI](#).

The following section shares some ideas provided by other parents and professionals related to four key areas: sleeping, eating, personal care and moving around.

Sleeping

Children with MSI may not easily establish regular patterns of sleep and wakefulness. This can be particularly hard for parents and carers, who need rest themselves. There may be a number of reasons - for example:

- the child's concept of day and night may not be established, particularly if they have a severe visual impairment
- children may need periods of rest or sleep during the day, which may disrupt their sleeping at night.

Here are some approaches that may help:

- Establish a regular routine for each day that your child can understand and anticipate.
- Try to make sure your child's room is evenly lit, and that there are limited distractions.
- Make sure your child has opportunities during the day for both exercise and rest.
- At the end of the day, introduce a consistent winding-down sequence of events that is mutually enjoyable. For example, dimmed lighting, a scented bath, being wrapped in a warm soft towel, a sequence of gentle massage and rocking songs. If you're relaxed and enjoying your child, these feelings will be transferred to them.



- A warm drink and biscuit or other light snack before bed may prevent hunger during the night and help to prolong periods of sleep.
- Warm the bed and dim lighting before entering the bedroom - this will encourage your child to snuggle and settle down.
- If you are worrying, think of installing CCTV or a listening service so you can observe your child without having to open the door and disturb them.

Don't hesitate to talk about your child's sleeping difficulties with your health visitor or GP if you need to.

Your need to sleep as well

If your child is regularly keeping you up at night, you should think about your own situation. Feeling tired over a long period of time can lead to exhaustion, which then becomes another problem. You may need to adjust, taking opportunities for rest whenever you can and at whatever time your child is sleeping. Having a night off (and a night out) on a regular basis can give you time for yourself, and your partner or friends, to think about other things or simply to catch up on your own sleep.

Eating and drinking

Many children with multi-sensory impairment are reluctant to eat. This can cause physical problems for the child and an emotional response in the family, because giving food is such a fundamental part of looking after a very young child.

Eating and drinking / feeding difficulties can be due to health problems such as:

- physical problems with the child's swallowing mechanism or the digestive system
- medical interventions, which may have been painful, uncomfortable or frightening. Children sometimes generalise these events and associate them with eating
- tube feeding through gastrostomy or naso-gastric tubes. Prolonged periods of tube feeding may mean that the child has to learn or relearn how to suck and feed.

If your child has a particular syndrome or condition you might want to check whether a physical problem has been identified as part of it. Other families with children with similar conditions may have ideas to help you. [Sense](#) or [Contact a Family](#) may also be able to help with advice.

Problems may also stem from a lack of opportunity to play with food and practise eating like other infants do. If your child is fed by having food spooned into their mouth, or by someone holding their hand onto a spoon, the process may be confusing or even frightening when the outcome is not pleasurable.

Here are some approaches that may help:

- Before you start, have a go at identifying the cause of any difficulties. This may help in deciding what to do. Other parents say they can respond more calmly if they understand why their child is behaving in a particular way. Remember that feeding problems usually develop very gradually, and may take some time to remedy
- Make sure you and your child are both positioned comfortably for eating.
- Cue your child in to what is about to happen. Use a bib or spoon as a consistent 'object cue' to signal that mealtime is about to start. Give the child time to smell and feel the food. Use a consistent signal, such as a touch on their hand, to show that the next mouthful is coming.
- Slow down your own movements and responses to give your child time to understand the information they're receiving.
- Allow and encourage your child to touch food - they may then take their hands to their mouth. Playing with soft, sweet foods (for example, yoghurt or mashed banana) sometimes encourages children to smell, touch and taste food in a way that reduces pressure on mealtimes.
- Try putting small bits of liquidised food on your child's bottom lip (not in the mouth), so that they are left free to decide whether to accept or reject it.
- Support your child in learning to feed themselves as they get older - for example, by helping them load the spoon and then letting them put it on their mouth. It may take a little time before they are ready. Many children with MSI will initially reject having their hands held or moved. They need to feel that they can control what is happening and can withdraw their hands when they want to do so.
- Praise positive responses and accept it when your child does not want to eat or do something. Try to stay relaxed!



Personal care

Sighted hearing children get lots of information about different aspects of their personal care, such as washing, dressing and going to the toilet. They see, hear and smell nappies and wipes being put ready, water running, bubbles from bubble bath and much more.

Children with MSI, in contrast, need to develop a routine that helps them to understand their own personal care and what happens. This helps them to participate more readily.

Toilet training is likely to take longer for children with MSI, and for some children with additional disabilities bowel and bladder control are hard to achieve. Most children, however, learn to co-operate in these routines.

Remember that most children are interested in their own body fluids. Children with MSI are no exception!

Here are some approaches that may help:

- Establish a regular routine for each day that your child can understand and anticipate.
- Cue your child in to what is about to happen. Indicate the stages of dressing through touch while at the same time saying, for example, 'This is going over your head'. You can then use touch, verbal and/or signed cues when the child needs to be lifted. Try to allow enough time to encourage your child to respond.
- As for all children, begin toilet training when your child is dry for longer periods and seems more aware of what is happening. Many children with multi-sensory impairment feel insecure in space and do not like sitting on a potty or toilet. Make sure your child's feet are supported on the floor or on a step, and that they have something or somebody (initially an adult) to hold on to.
- Bathrooms smell different from other rooms, and often echo. Some children with MSI find this interesting, and experiment with sounds; others find it frightening. Bathrooms need to be made friendly (perhaps with scented soap and relaxing music), especially for those children who become anxious there.

- Children who are anxious about going to the bath may prefer a baby bath so that they can feel the edges - or they may prefer to share a bath with you.
- If your child's behaviour is socially unacceptable when wet or soiled, first check whether there are any new physical or medical problems.
- For young children, all-in-one sleepsuits help to stop them removing their nappy. For older children, dungaree-style sleep suits can be made (the arms and neck need to be quite high).
- Praise positive responses. If your child does not want to do something, show them that you understand how they are feeling, even if you have to insist that the personal hygiene activity is done.

Moving around

Sighted hearing babies generally begin to move because they see interesting things (or people) that they want to reach. Children with MSI are often slower to move independently, and need extra help. Some also have additional physical problems which affect their movement, and some have difficulties with balance and with knowing where they are in space.

Physiotherapists can help with movement and positioning, especially for children with additional physical problems. Specialist **teachers of children with visual impairments**, or **teachers of children with MSI**, can suggest ways to encourage your baby to move.

Here are some approaches that may help:

- Try to lie your baby down in different positions, not always on their back. This can be difficult if your baby has physical problems or even just a strong preference for one position.
- Children need to experience different positions and movements through space. If you carry them with you when you can, in a baby sling or backpack, then they experience movement whilst feeling secure because they are close to you. Slings and backpacks are useful indoors as well as out.
- Bouncy chairs and baby swings at the park also give different sensations of movement. Many older children with MSI love fairground rides (often more than their parents do!)
- Many children with MSI find large spaces threatening or simply too big to understand. They may be more willing to move and explore in a very small environment. This could be a baby nest or a large cardboard box turned on its side. There are also purpose-built 'Little Rooms' that your specialist teacher may be able to arrange for you to borrow. One advantage of small environments is that they keep different textures and objects within the child's reach. With a



cardboard box or Little Room, objects can be attached to the sides and roof, so that any movement by the child brings them into contact with something interesting.

- When children are learning to walk, pushalong toys can be helpful, because they give the child something to hold on to and protect them from bumping into walls or furniture.
- It helps if you can keep the furniture in the same places over time, and also if you can arrange it so that your child can find their way across a room by moving from piece to piece - this is easier than crossing large spaces. However, you need to consider the needs of other members of the family, and can only do what is practical for you.
- If your child begins to move away from you to explore, it's tempting to think that they are happy playing and to go and do something else. Stay put. Children usually explore a little and return to their carer, explore and return, explore and return... A child with MSI may not be able to see or hear you if you move away, and may not know how to find you again. If they lose you, they're less likely to explore next time.

Your home environment

Your child's surroundings can encourage them to explore and learn, or teach them that it's not safe to do so. The following ideas may help children to get as much information as possible about the world around them, although not all the points apply to every child. It's important that the rest of the family isn't left out of decisions about how space is used. This is your home and it's a shared space for everyone.

- Try to provide a good level of even light wherever possible. If your child has to move between brightly and dimly lit areas, give them time to adjust.
- Where possible, use contrasting (ie light and dark) colours to distinguish different areas, for example, doors from walls.
- Try to avoid glare (reflected light bouncing off shiny surfaces). Use curtains or blinds at windows, and matt rather than shiny surfaces if possible.
- Avoid clutter - as far as you can!

- If you're playing with your child, turn the television and radio off and reduce other background noise as much as possible. This will make it much easier for them to use any hearing they have.
- Carpets and curtains help to deaden echoes in rooms. Be aware that children who wear hearing aids suffer in noisy, echoing spaces such as dining rooms with wooden floors.
- Position furniture to establish clear routes around a room. Avoid large open spaces, as your child will find it very hard to work out where they are in these situations.
- Be aware of textures, on toys and other objects, on walls and underfoot. Textures can help your child recognise objects and places.
- Be aware of smells and air currents that might help your child to recognise places and activities. This is harder than it sounds - we often don't notice the subtle changes in air pressure, for example, that a child with MSI may pick up.

Think about the information your child receives from their surroundings during particular activities and ask yourself:

- What information is irrelevant or distracting - could it be removed or lessened?
- What information is relevant and helpful - could it be improved?
- A wide range of special equipment is used with children with MSI. Some is used by other children as well - for example, soft play equipment. Other equipment is designed especially for children with complex needs. **Resonance boards**, for example, are raised plywood platforms on which children can lie - any movement the child makes gives them vibro-tactile feedback.

Different professionals can advise you about different kinds of equipment:

- **physiotherapists** can tell you about equipment to help your child move and use the best positions for different activities
- **occupational therapists (OTs)** can tell you about equipment to help with everyday living activities
- **speech and language therapists** can advise about communication aids of different kinds and sometimes about aids for eating and drinking.
- **specialist teachers for children with MSI**, or **hearing impairment**, or **visual impairment** can talk to you about equipment to help your child play, learn and communicate.



Thinking about social care and education

Early intervention

Depending on your child's needs, you may be offered help by a number of professionals working for different agencies. Although they have expertise in the kind of needs your baby has, you know more about your child than anyone else, and all the other people involved will recognize this. Professionals need and want to work with parents as partners, in order to help children develop as well as possible.

A range of professionals working with parents will carry out early assessments of a child's needs. This should (but may not always in practice) be done in a co-ordinated way, and should lead to a plan which details:

- the child's needs
- the early intervention to be provided.

Children with identified special needs can receive additional help from diagnosis onwards. Specialist teachers may visit the family's home, or other provision may be made. Children with special needs may sometimes be offered a school place from the age of two. Parents should be fully involved in deciding what form of help is most appropriate.

'One of the first sources of support was from an MSI teacher. I felt she understood the various aspects of our son's syndrome and had worked with quite a few children with the same condition - knowing this was really important to me. She was very positive about our son's abilities, which in turn helped us feel more positive.'

Social care for deafblind children and adults - Deafblind guidance

The guidance says that local social services departments or children's departments must assess every deafblind child in their area for services and then provide what that child needs, including one-to-one support, if needed, perhaps through an intervenor. Support can also include aids or adaptations for the home.

To see whether you are entitled to help, ask Social Services or the Children's Department to assess your child in accordance with 'Social Care for Deafblind Children and Adults' LAC (DH) (2009) 6.

Assessment must be made by specialists trained in deafblindness - check that this is the case. The authority can buy in an assessment from an organisation like [Sense](#) if need be. The assessment includes areas like:

- communication
- one-to-one support and social interaction
- mobility
- technology which could help.

It should take account of current needs and expected needs in the future. This is especially important for children whose sight or hearing is likely to change over time.

You should be fully involved in the assessment - you know your child best. After the assessment, you should receive a document clearly setting out your child's needs and how the authority plans to meet them. Local authorities must meet the needs they have assessed, even if this means employing or training new staff.

The following case studies show how the system works. Some local authorities are more experienced than others in providing Deafblind Guidance assessments and help. If you experience any difficulties with the process, ring [Sense](#).

Leon is visually impaired and has a profound hearing loss. He is four years old, and has had support (with joint agency funding) since he was two. His assessment showed that he needed one-to-one support from an intervenor. At first this support was provided at home on three days a week, to help with communication, movement and play. Then, when Leon began attending an assessment nursery part-time, his intervenor went with him, increasing the level of intervention to 5 days a week (6 hours a day), with the remaining time spent in the home. Currently Leon attends the nursery class of a special school for children with visual impairments, again accompanied by his intervenor for 3 days a week. As his education continues, he will still receive intervenor support out of school hours to help him access activities at home and in the community.



Eleanor is profoundly deaf and visually impaired. When she was four years old, a Sense advisory teacher told Eleanor's mother about the Deafblind guidance. Her parents applied to their local authority, which asked Sense to carry out Eleanor's assessment. The assessment showed that Eleanor needed one-to-one support at home and in the community, both to help carry out activities suggested by the physiotherapist, the local Sensory Support service and others (including weekly visits to the local hydrotherapy pool), and also to let Eleanor's mother spend some uninterrupted time with Eleanor's younger brother. Unfortunately, arguments about who should fund the support led to a year-long delay in providing services. Eleanor's parent persisted, and Eleanor now has one-to-one support from an intervenor every weekday afternoon, with additional time at weekends and during school holidays.

Having 'an assessment under the Deafblind Guidance, as it is often called, for these social and community-based activities will not adversely affect your child's educational support. You don't have to choose - your child is entitled to both.

Working with a number of professionals

Children with MSI frequently have complex medical and educational needs, and, because of this, many families receive services from a number of different professionals. These services need to work together in a co-ordinated way so that families gain the most benefit - for example, doctors and allied professionals may be able to arrange joint or consecutive appointments, while educational specialists and **physiotherapists** may visit the home together to co-ordinate their input.

In some areas **key workers** work to co-ordinate services and arrange support in the way that is most useful to the family. Professionals should explain what they are doing and why, and also share and explain the results of any assessments that are carried out. You may want to ask for copies of reports or assessments if you're not offered them straight way. Ask questions about anything you don't understand or disagree with.

It is important that you tell professionals about any cultural and religious needs your family may have. If your home language is not English, you can ask for an interpreter to be present at meetings. Make sure that you ask well before the meeting, to give time for this to be arranged. If you have a hearing impairment, you can ask for a sign language interpreter.

Many families report the demoralising effect of having to repeat a list of their child's disabilities and needs to every new doctor, nurse, therapist and teacher that they meet. Parents also comment that they are often asked to talk about what their child can't do rather than say anything about the things that they can do.

The [Early Support Family file](#) can help with some of this and families who receive regular support from a number of different agencies or people will probably find the [Early Support Family pack](#) useful. It provides information and materials designed to help with the co-ordination of services as well as the [Family file](#). Ask the people who work with you about this pack or look at the back of this booklet to find out more.

Choosing a playgroup, nursery or school

Children who need extra or different help than other children of the same age are said to have [special educational needs](#). And children with special educational needs are entitled to appropriate educational support. You can read more about this in another [Early Support](#) publication - the [Background information booklet on Education](#).

Some particular issues apply in the case of children with MSI. For most children, for example, [inclusion](#) means education in mainstream settings with non-disabled children. For children with MSI, inclusion may mean that they are educated with children with other disabilities (for example, single sensory impairments) whose communication systems or other needs are similar to theirs. Some children with MSI are supported by [intervenors](#). These are specialist learning support assistants, who work one-to-one with children with MSI. They provide information that would normally come through sight or hearing and help children to understand, to communicate and to access their environment.

Choosing a school or nursery for your child is a very personal decision. You might want to think about some of the following points, which are particularly relevant for children with MSI. Some of the questions clearly have right and wrong answers, but many do not - they depend on your preferences and what you want for your child.

- How do staff get on with your child at first meeting? Are you happy with their attitude and style of working? How does your child react to them?
- What resources does the setting have? Ask about qualified specialist teachers, access to medical and therapy staff if appropriate, and other specialist resources.



- Are **teachers of the deaf, teachers of children with visual impairment or teachers of children with multi-sensory impairments** involved? Can they support your child and staff in this setting?
- Who exactly will work with your child? If they don't yet know, how will they decide? How many children are there for each member of staff?
- How does the head teacher describe the main aims of the school?
- Does it sound as though your child will be included?
- How much, if anything, do staff members know about MSI? What training have they had in multi-sensory impairment? If your child will be supported one-to-one, is this by a trained **intervenor**? Does your child's teacher have the mandatory qualification in the education of children with multi-sensory impairment?
- Are there any other children with similar needs to your child?
- What communication systems are used? How will your child communicate with staff, peers and other people?
- How will information be presented to your child?
- Is the physical environment appropriate? Will your child be helped or hindered in seeing, hearing and moving about? Is appropriate special equipment available?
- How much choice will your child get regarding activities? Will they be included in all school activities? If not, then which areas will they be included in and why?
- What curriculum will your child follow? Is it the same as that followed by the other children?

Some children with MSI have joint placements, spending part of their time in one setting (perhaps a mainstream nursery or school) and part in another (perhaps a specialist setting). This can work well for some children, and may give the flexibility to change arrangements when needed - for example, as the mainstream curriculum becomes more academic. However, it means that children must deal with two sets of people, activities and environments. Sometimes the same **intervenor** works with the child in both settings, to ensure continuity.

Transition

Transition means moving from one setting to another - for example, beginning playgroup after being at home full-time, or moving from nursery to school. Children with MSI need special help with transitions, because they get so little information that it takes them longer to learn about new people, places and activities. This means that new settings may be confusing and frightening for them.

The following approaches may help.

Staff from the new setting may visit the child's home and/or playgroup, nursery or school before transition. This will help them become familiar to the child and also to learn more about particular likes and dislikes and important routines. If possible, make the move gradually, with regular visits to the new setting for slowly increasing periods of time. It may be possible for the child's [intervenor](#) or another familiar adult to spend the first few weeks with the child in the new setting, gradually handing over to new staff.

The communication system used with the child should be the same in the new setting, at least to start with - the same cues for activities, the same ways of explaining what is happening and some of the same routines.

Changes are very tiring for children with MSI, because of the new information involved. It helps if children are given frequent chances to rest and relax, perhaps in a special, secure place that they can easily find when they need to (a beanbag seat, for example). Children who wear school uniform may find it easier if they have worn the clothes at home beforehand, so that they don't seem new or strange.

Families who use an [Early Support Family file](#) may find it particularly helpful at times of transition as it helps them to introduce their child to new people and to describe the support that is already in place. Sometimes staff at a 'new' setting may not be used to planning transition in such detail, especially if they have little experience of children with MSI. The professionals already involved with your child can discuss the need for flexibility and preparation with them



Home-school communication

Your child may travel to nursery or school in local authority transport, usually a minibus or taxi. This means that you won't be able to talk to school staff as easily as if you collected your child everyday from the school playground. There are usually several different ways of staying in contact with the school - for example, daily home-school diaries, parents' evenings and other meetings and the opportunity to phone or visit. If you are not comfortable with the systems in place, or would find something else more helpful, say so. For example, if a written home-school diary is not helpful, it may be possible for staff to record a spoken message each day and send this home.

Who can help?

Sources of help and support

Professional help for families with children with MSI can come from many sources. In the early years there may be contact with [health visitors](#), [GPs](#) and other medical staff, [specialist teachers](#), perhaps [intervenors](#), and therapists such as [physiotherapists](#). Different professionals may be involved at different times, as children's needs change. You can read more about this in the next section.

Many families find contact with other families very helpful. There may be local support groups, but because MSI is very rare it may be hard to meet other families with children with similar needs. Two voluntary organisations might be able to help with this. [Contact a Family](#) is an umbrella organisation of support groups, and Sense has regional branches and a national family network.

Contact a Family

[Contact a Family](#) helps families who care for children with any disability or special need. They are a main source of information about rare disorders and are able to put families in touch with one another.

209-211 City Road
London EC1V 1JN

Freephone Helpline: 0808 808 3555
Textphone Helpline: 0808 808 3556
Tel: 020 7608 8700
Fax: 020 7608 8701

Email: info@cafamily.org.uk
Web: www.cafamily.org.uk



Sense

Sense (the National Deafblind and Rubella Association) is the major UK voluntary organisation for people born with MSI. They campaign for better services and support for children and adults with MSI and for their families. Sense also provides services - notably the Sense Children's Specialist Service, which offers assessment and support to children with MSI and to their families.

Sense branches are regional groups of people affected by or interested in MSI. Other Sense Networks provide opportunities for the families and friends of children with MSI to meet and stay in contact. Sense also publishes a magazine (called Talking Sense) three times a year.

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Professionals and what they do

Because children with MSI often have very complex needs, families may meet a range of professionals, each with a different role. The list below explains what some of the different professionals do. A fuller list is given in another [Early Support](#) publication - the [Background information booklet](#) on [People you may meet](#).

Audiologist

An **audiologist** advises on hearing, carries out hearing tests, and explains the results of those tests. If your child needs hearing aids they will establish the best type and arrange for you to get them. They will also monitor your child's hearing to make sure that any hearing aids supplied are appropriate.

Care staff

Care staff are employed to provide short breaks to families, on an occasional or regular basis, by providing alternative care for their child.

Ear, nose and throat (ENT) consultant

An **ENT consultant** is a doctor who specialises in the diagnosis and treatment of ear, nose and throat conditions. When a hearing loss has been identified, they can help in trying to discover the cause of deafness.

Educational audiologist

An **educational audiologist** is a qualified teacher of the deaf who has an additional qualification in audiology including hearing assessment. They give guidance to teachers of the deaf, parents and other professionals about hearing assessments, hearing aids and hearing support.

Educational psychologist

An **educational psychologist** has a degree in psychology and additional specialist training. Educational psychologists help children who find it difficult to learn or to understand or communicate with others. They can assess your child's development and provide support and advice.

General Practitioner (GP)

A **GP** is a family doctor who works in the community. They are often the first point of contact for families. They deal with your child's general health and can refer you on to clinics, hospitals and specialists when needed.



Health visitor

A **health visitor** is a health professional who visits family homes in the early years to check on children's health and development. They give help and advice to families about the care of very young children, normal child development, sleep patterns, feeding, behaviour and safety. You should automatically receive a visit from a health visitor, as all families are visited in the early years. If you don't, they can be contacted through your GP.

Intervenor

An **intervenor** is a specialist learning support assistant who works one-to-one with a child or adult with MSI, providing information that would normally come through sight or hearing and helping the child to understand, to communicate and to access the environment.

Key worker/link worker/care co-ordinator

A **key worker** acts as the co-ordinator of services for a particular child, working to make sure that the help offered is what parents find most useful and is organised in the way that best suits their child's needs. This is usually one of the professionals already involved with the child and family; they can come from any of the different services.

Learning support assistant/teaching assistant

A **learning support assistant** or **teaching assistant** is someone who works in early years settings or in the classroom, alongside the teacher, supporting individual children or those in small groups to learn effectively, participate and reach their potential.

Mobility officer/mobility teacher

A **mobility officer** is someone trained in teaching mobility skills to people with severe visual impairments (not necessarily to children or those with additional disabilities). They encourage children with a visual impairment to move around more independently.

Neurologist

A **neurologist** is a doctor who specialises in the brain and nervous system.

Occupational therapist

An **occupational therapist** helps children improve their developmental function by therapeutic techniques and advises on environmental adaptations and the use of specialist equipment. OTs are concerned with difficulties that children have in carrying out the activities of everyday life.

Ophthalmologist

An **ophthalmologist** is a doctor based in a hospital who specialises in the diagnosis and treatment of eye defects and diseases. They have special qualifications and experience in eye disorders and in treating them with appropriate medicine and surgery.

Optician

An **optician** is trained to dispense and adjust spectacles and other optical aids. Ophthalmic opticians also carry out sight testing and prescribe spectacles, although young children with MSI are more likely to be assessed at a specialist clinic.

Orthoptist

An **orthoptist** is a health professional who specialises in the treatment of correcting vision by non-surgical measures (especially by exercises to strengthen the eye muscles). They can test children's sight, look at eye movements, assess how well both eyes work together and check for squints.

Paediatrician

A **paediatrician** is a doctor who specialises in working with babies and children. They can offer advice, information and support about any medical condition(s) your child has. It is usually a paediatrician who refers your child on to any specialists that they need to see.

Physiotherapist

A **physiotherapist** is a health professional who specialises in physical and motor development. They may show you exercises for your child and discuss ways of developing good movement patterns. They can also offer advice on the best way to carry, hold and position your child.

Portage home visitor/Portage worker

A **Portage home visitor** is someone who has received training from the National Portage Association to work with you and your child. Portage is a home-based educational support service for pre-school children with additional support needs which may be provided by a local authority.



Social worker

A **social worker** is a professional who supports children and families by advising on appropriate services and introducing families to some of the services they need. They provide practical help and advice about counselling, transport, home helps and other services. They may also be able to help you with claiming welfare benefits and obtaining equipment you need at home. In some areas, social services have specialist social workers who have particular knowledge and experience of working with learning disabled, blind or deaf people. In other areas, social workers work within teams supporting a range of disabled children.

Special educational needs co-ordinator (SENCO)

A **SENCO** is a teacher who has particular responsibility for ensuring that all children with special educational needs are receiving the provision they need. Some **Early Years Area SENCOs** work across a number of different early years settings.

Specialist teachers

A **specialist teacher** has additional training and qualifications in a particular area. Three types of specialist teacher commonly work with children with multi-sensory impairments: **teachers of children with MSI**, **teachers of children with visual impairments** and **teachers of children with hearing impairments** (also called teachers of the deaf). **Teachers of children with MSI** provide support to children with MSI, their parents and family, and to other professionals who are involved with the child's education. **Teachers of children with visual impairments or hearing impairments** can provide specialist input relating to these needs.

Speech and language therapist

A **speech and language therapist** is a health professional specialising in communication development and disorders. They offer support and advice to parents of children with any type of communication problem. They work to enable children to develop their communication skills, in sign language, spoken language or other systems, and can provide additional communication aids if needed. Some speech and language therapists also specialise in feeding, eating or swallowing disorders.

Support groups and useful organisations

Advisory Centre for Education (ACE)

ACE is a national charity that provides advice and information to parents and carers on a wide range of school based issues including exclusion, admissions, special education needs, bullying and attendance. They are passionate about education and the difference that education can make to the lives of children and young people..

1c Aberdeen Studios
22 Highbury Grove
London N5 2DQ

Helpline: 0808 800 5793
Fax: 020 7354 9069

Email: enquiries@ace-ed.org.uk
Web: www.ace-ed.org.uk

Carers UK

A registered charity that provides support to anyone who is a carer. They offer information and advice and produce a range of publications and also campaign for carers' rights. Carers run the organisation.

20 Great Dover Street
London SE1 4LX

Advice line: 0808 808 7777
Tel: 020 7378 4999
Fax: 020 7378 9781

Email: adviceline@carersuk.org
Web: www.carersuk.org



CHARGE Syndrome Family Group

The word CHARGE is made up from the initial letters of some of the most common features seen in this condition – the 'E' is for Ear anomalies. It is a syndrome with multiple conditions, which include hearing loss. The group supports a network of families who aim to promote and support all activities leading to an improved quality of life for their children.

59 Elmer Road
London SE6 2HA

Tel: 020 8265 3604

Email: si_howard@hotmail.com

Web: www.chargesyndrome.org.uk

Citizens Advice Bureau

The Citizens Advice Bureau helps people resolve their legal, money and other problems by providing free, independent and confidential advice, and by influencing policymakers.

Myddleton House
115-123 Pentonville Road
London N1 9LZ

Tel: 020 7833 2181 (admin only- no advice available on this number)

Fax: 020 7833 4371

For information about local offices see - www.citizensadvice.org.uk or www.adviceguide.org.uk or look under C in the Yellow Pages.

Contact a Family

Contact a Family helps families who care for children with any disability or special need. They are a main source of information about rare disorders and are able to put families in touch with one another.

209-211 City Road
London EC1V 1JN

Helpline: 0808 808 3555
Textphone: 0808 808 3556
Tel: 020 7608 8700
Fax: 020 7608 8701

Email: helpline@cafamily.org.uk
Web: www.cafamily.org.uk

Crossroads- Caring for Carers

Crossroads Care promotes and supports a network of local Crossroads Care charities across England and Wales. Crossroads Care work with more than 35,000 individuals and their families, helping carers make a life outside of caring, providing flexible services to people of all ages and with a range of disabilities and health conditions. For information on local services see the local support section on their website.

10 Regent Place
Rugby
Warwickshire CV21 2PN

Tel: 0845 450 0350
Fax: 01788 565 498

Email: communications@crossroads.org.uk
Web: www.crossroads.org.uk



Genetic Interest Group

The Genetic Interest Group (GIG) is a national alliance of organisations which support children, families and individuals affected by genetic disorders. Its primary goal is to promote awareness and understanding of genetic disorders so that high quality services for people affected by genetic conditions are developed and made available to all who need them. GIG publishes a quarterly newsletter and seeks to educate and raise awareness amongst opinion formers, people of influence and the public about human genetics and genetic disorders.

Unit 4D Leroy House
436 Essex Road
London N1 3QP

Tel: 020 7704 3141
Fax: 020 7359 1447

Email: mail@gig.org.uk
Web: www.gig.org.uk

Mencap

Royal MENCAP Society is a registered charity that offers services to adults and children with learning disabilities. They offer help and advice in Benefits, Housing and Employment. They also offer help and advice to anyone who has any other issues or they can signpost them in the right direction. They can also provide information and support for leisure, recreational services (Gateway Clubs) residential services and holidays.

4 Swan Courtyard
Charles Edward Road
Birmingham B26 1BU

(please note, this address is due to change towards the end of 2010 – contact the office for further details)

Learning Disability Freephone Helpline: 0808 808 1111
Learning Disability Typetalk: 18001 0808 808 1111

Email: helpline@mencap.org.uk
Web: www.mencap.org.uk

National Deaf Children's Society

Supports families of deaf children. They provide clear and balanced information on all aspects of childhood deafness, including temporary conditions such as glue ear. They also campaign on behalf of deaf children and their families. They provide opportunities for young deaf people to develop social skills, confidence and independence and work with professionals and policy makers to ensure high quality services are available for all.

15 Dufferin Street
London EC1Y 8UR

Helpline: 0808 800 8880 (Voice and text)
Tel: 020 7490 8656 (General enquiries)
Fax: 020 7251 5020

Email: helpline@ndcs.org.uk
Web: www.ndcs.org.uk

The Princess Royal Trust for Carers

A registered charity providing information, support and practical help for carers. It runs a national network of 144 independently-managed Carers' Centres across the UK to work with families and others in their local communities.

Princess Royal Trust for Carers
The Princess Royal Trust for Carers
Unit 14, Bourne Court
Southend Road
Woodford Green
Essex IG8 8HD

Tel: 0844 800 4361
Fax: 0844 800 4362

Email: info@carers.org
Web: www.carers.org



Royal National Institute of Blind people (RNIB)

RNIB education services work to ensure children and adults with sight problems gain access to the best education opportunities at home, school, university and in the wider community. RNIB provides a range of services for children who are visually impaired including those who have additional needs. These services include information, advice and guidance, training, consultancy, independent specialist assessments, vacation schemes, family weekends and activity days.

105 Judd Street
London WC1H 9NE

Helpline: 0303 123 9999
Tel: 020 7388 1266 (General enquiries)
Fax: 020 7388 2034

Email: helpline@rnib.org.uk
Web: www.rnib.org.uk

Royal National Institute for Deaf People (RNID)

Aims to achieve a better quality of life for deaf and hard of hearing people. It does this by campaigning, lobbying, raising awareness of deafness, by providing services and through social, medical and technical research.

19-23 Featherstone Street
London EC1Y 8SL

Tel: 020 7296 8000
Textphone: 020 7296 8001
Fax: 020 7296 8199
Information Line (Freephone): 0808 808 0123
Textphone: 0808 808 9000
SMS: 0780 000 0360

Email: informationline@rnid.org.uk
Web: www.rnid.org.uk

Scope

Scope's focus is on children and adults with cerebral palsy and people living with other severe and complex impairments. Their vision is a world where disabled people have the same opportunities to fulfil their life ambitions as non-disabled people..

6 Market Road
London N7 9PW

Helpline: 0808 800 3333
Text: SCOPE plus message to 80039

Email: response@scope.org.uk
Web: www.scope.org.uk

Sense

The major UK voluntary organisation for people born with MSI. They campaign for better services and support for children and adults with MSI and for their families. They also provide services offering assessment and support to children with MSI and to their families. Sense Networks provides opportunities for the families and friends of children with MSI to meet and stay in contact.

Head Office
101 Pentonville Road
London N1 9LG

Tel: 0845 127 0060
Text: 0845 127 0062
Fax: 0845 1270061

Email: info@sense.org.uk
Web: www.sense.org.uk



Websites

There are a number of websites that offer information and advice on multi-sensory impairment. As with any information from the web, there can be no guarantee of accuracy or lack of bias. The following sites are ones that other families have found useful.

Contact a Family (www.cafamily.org.uk) provides support and advice to the families of children with special needs. The website has information on a huge range of rare syndromes and rare disorders, together with relevant support groups. There are factsheets available on a range of issues (for example, benefits, siblings, education).

DBLink (www.nationaldb.org) is the US National Information Clearinghouse on Children who are Deafblind. The site has lots of information, including articles, links, bibliographies on a range of subjects, and the online version of the journal *Deafblind Perspectives*.

The National Deaf Children's Society (NDCS) (www.ndcs.org.uk) provides information about childhood deafness.

The **Royal National Institute for Deaf People (RNID)** (www.rnid.org.uk) website has information related to deafness, including factsheets on a range of issues.

The **Royal National Institute of Blind People** (www.rnib.org.uk) website contains a mass of information on visual impairment. There are a number of factsheets, including many relevant to people with multiple disabilities.

Sense (www.sense.org.uk) is the major UK voluntary organisation for children and adults born with MSI and their families. The website has information about multi-sensory impairment and about the help and services available to people with MSI, their families and professionals.

SCOPE (www.scope.org.uk) works with people with cerebral palsy. The site has information including factsheets on a range of topics (for example, therapies, behavioural issues, educational needs).

The **Sense Scotland** (www.sensescotland.org.uk) website has information and a range of links particularly to Scottish organisations.

The [Scottish Sensory Centre \(www.ssc.education.ed.ac.uk\)](http://www.ssc.education.ed.ac.uk) site has a huge amount of useful information. It includes the Sensory Information Service (a UK wide information service for those involved with people with hearing and/or visual impairments). This has a database of information on everything from service providers to types of hearing aid. The site also includes a number of papers and links to many other useful articles.

[Visual Impairment Scotland \(www.viscotland.org.uk\)](http://www.viscotland.org.uk) is a user-friendly site with access to specialist information about visual impairment. Home of Viskids.

Glossary

British Sign Language (BSL) - a visual language used by deaf people.

Inclusion - the practice of educating and supporting children with special educational needs in mainstream schools.

Intervenor - An **intervenor** is a specialist learning support assistant who works one-to-one with a child or adult with MSI, providing information that would normally come through sight or hearing and helping the child to understand, to communicate and to access the environment.

Makaton - a form of sign language often used with people who have learning disabilities

Objects of reference - an object linked with or used to represent a familiar routine or activity - for example, a spoon to represent 'dinner time'. Sometimes also called **object cues**.

Special educational needs (SEN) - describe the support that a child with learning difficulties needs in pre-school settings or schools. Children with special educational needs require extra or different help from that given to other children of the same age.

Special educational provision - extra or different help provided to support children with **special educational needs**. The legal definition is:

- For children of two or over, educational provision that is additional to or otherwise different from, the educational provision made generally for children of their age in schools maintained by the local authority in the area
- For children under two, educational provision of any kind.

Tactile defensiveness - refusal to touch things. Hand are often withdrawn.

Tactile sensitivity - distress or discomfort resulting from touching certain textures.

About Early Support and the materials

Early Support is the Government's programme to improve the quality, consistency and coordination of services for young disabled children and their families across England. Early Support is funded and managed by the Department for Children Schools and Families (DCSF) and is an integral part of the wider Aiming High for Disabled Children (AHDC) programme, jointly delivered by DCSF and the Department of Health. The AHDC programme is seeking to transform the services that disabled children and their families receive.

Early Support is targeted at families with babies or children under five with additional support needs associated with disability or emerging special educational needs although the principles of partnership working with families can be applied across the age range. This partnership working between families and professionals means that families remain at the heart of any discussions or decisions about their child - their views are listened to and respected and their expertise is valued by the professionals working with them.

To find out more about the **Early Support** programme and associated training or to view or download other materials produced by the programme, visit www.dcsf.gov.uk/everychildmatters/earllysupport

This booklet is one in a series produced in response to requests from families, professional agencies and voluntary organisations for better standard information about particular conditions or disabilities. This is the third edition of the booklet, which up-dates information and incorporates comments from those who used the material in 2004-2009.

This booklet is one in a series produced in response to requests from families, professional agencies and voluntary organisations for better standard information about particular conditions or disabilities. The other titles in the series are:

Cerebral palsy (ES10)

Down Syndrome (ES13)

Autistic spectrum disorders and related conditions (ES12)

If your child has a rare condition (ES18)

Deafness (ES11)

Speech and language difficulties (ES14)

Visual impairment (ES8)

When your child has no diagnosis (ES16)

Three additional Information for parents booklets, one on Sleep, one on Neurological disorders and one on Behaviour will be available by Spring 2010.

Other **Early Support** information about services is available separately, or as part of the **Early Support Family pack**. The **Family pack** helps families who come into contact with many different professionals to co-ordinate activity and share information about their child through the first few years of life, using a Family file.

These are resources that families say make a difference. If your family is receiving regular support from professionals, please feel free to ask them about the **Early Support family pack**. It may help and is available free of charge.

Early Support would like to thank the many families and professionals that have been involved in development of these resources and to thank **Sense** and all the parents and families who were involved in producing this material for their help in writing and more recently revising this booklet.



Sense is the national charity that supports and campaigns for children and adults who are deafblind and multi-sensory-impaired. It provide specialist information, advice and services to deafblind people, their families, carers and the professionals that work with them. This includes: offering family support; specialist assessment and advice on educational and social care choices; a holiday programme; and opportunities to meet other families through a networks and local branches. It also provides advice and training for professionals from all agencies, who work with multi-sensory-impaired infants and children.

Copies of this publication can be obtained from:

DCSF Publications
PO Box 5050
Sherwood Park
Annesley
Nottingham NG15 0DJ

Tel: 0845 602 2260
Fax: 0845 603 3360
Textphone: 0845 605 5560

Please quote ref: ES9

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or e-mail: licensing@opsi.gsi.gov.uk

4th edition

www.dcsf.gov.uk/everychildmatters/earllysupport

We acknowledge with thanks the contribution of the following organisation in the production of this resource.

