

Information for parents

Multi-sensory impairment







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In the beginning

When a child is born with complex needs

The birth of a child is a major cause for celebration in any family, bringing it 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 this 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, as they cannot know what to expect for their child. It is like entering a new world.

Multi-sensory impairment (MSI)

Multi-sensory impairment 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 is very hard to come to terms with.

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.

How are you feeling?

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. Everybody's feelings will change over time.

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 therefore 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 families, over time begin to have suspicions about their baby's development. Families in this situation often face their biggest worries, 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 your family and friends can give you a bit of space to enjoy and get to know your new baby.



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, the 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 have taken place and, as a result, developing a bond with your baby may feel more difficult. In addition, 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 helps families to find ways of making a connection to start the relationship developing.

Support is available

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 is more information about how voluntary organisations can help put you in touch with other families later.

Read more about this in [Who can help?](#)

This booklet provides a short introduction to sources of 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.

Read more about this in [Professionals and what they do](#)

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?

Multi-sensory impairment

Children with MSI (multi-sensory impairment) have impairments of both vision and hearing. A very small number of children with MSI are totally blind and deaf, but most have some useful vision and/or hearing. Many children also face other challenges, such as medical conditions or physical disabilities.

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 is no single main cause. For some children, the cause of MSI is not known but, increasingly, diagnosis of the conditions that can cause it is improving.

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 quite 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 is 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 is 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- 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.

How MSI affects children's development

The effects of MSI on development are not simply those of hearing impairment plus those of visual impairment. Multi-sensory impairment effectively restricts experience to the here-and-now – what is happening at this moment, within arm's reach. The effects on development are wide-ranging.

- 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 do not see or hear the smiles, looks and speech to which most babies respond. 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.

- Seeing their surroundings plays an important part in motivating children to learn to move independently. Sight also motivates children to learn how to use their hands – essential for most children with MSI, who use their hands for exploration, information and communication to a much greater extent than sighted hearing children.
- Learning to explore their surroundings helps children to understand and control them. Children with MSI often have problems generalising skills and concepts from one situation to another, because they do not see the similarities or differences between different situations. MSI also reduces children’s ability to anticipate events – to know what is likely to happen to them next – and this makes exploration harder.
- Children with MSI cannot learn by watching what happens around them, as sighted hearing children do. MSI also makes children learn slowly. This does **not** mean that they necessarily have cognitive learning difficulties. Interpreting limited, poor-quality auditory or visual information, or learning through touch, are very slow processes indeed compared to using full sight and hearing, but they can be effective.

These are the big challenges that MSI children face, but, with the right support, they can maximise their use of vision and hearing and develop the confidence to be inquisitive and start exploring.



Getting started

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.

- **Building trust**

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. You can 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 particular 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 some additional measures to make sure the contact is fun.

- **Being supportive**

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.

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 usually have more fun on the Big Dipper than their parents!

- **Following the child**

Wherever possible, allow your child to control what is happening. Many children with MSI feel that they **cannot** affect what happens to them, give up trying, and hence stop learning.

Children with MSI may respond to signals that sighted hearing adults are not even aware of – the draught from an open door, for example. If you notice this happening, you can follow it up, so the significance of the information can be explained to the child by linking it to something recognisable. In supporting your child in this way you will begin to tune in to some of their characteristic ways of behaving and start to interpret what they do. You will soon notice the more intentional signs that indicate, for example, that your child is ready to move on to another activity, or when they would like to repeat it.



Helping your child to understand 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. Parents or carers can help to overcome these difficulties and make the world more understandable in the following ways:

- **Being consistent**

Children with MSI receive so little information from the world around them, that events need to happen very consistently if they are to make any sense. Objects that refer to a person or an activity can be used to help this process.

You can develop set routines – for example, dressing your child, getting ready for dinner or saying goodbye in the same way every time you do it. If possible, you should be as consistent as possible, using the same place, the same person and the same objects every time. With family life, this can be difficult (or even impossible at times) but you may want to give it a try to help your child recognise and understand the routine.

It may also help in the early days if the physical environment is laid out in the same way, with furniture always in the same place. This promotes mobility, giving the child the opportunity to learn, while exploring safely. It will, however, also have an impact on brothers and sisters who have games of their own to play!

- **Helping understanding**

You will need to tell your child what is happening, and what is going to happen, in a way they can understand. Cues (such as an armband for swimming, or a particular song for going out in the car) can be used to mark the beginnings and ends of events and to help identify activities. Some children will develop the use of speech or signing or other communication modes, but they **all** need help to anticipate what will happen next.

A good way to develop participation in activities is to encourage your child to touch, smell or taste – for example by holding their hands over yours while you make a drink, mix paint or put the toothpaste on the toothbrush. It is not unusual for children to explore objects using their feet, and so if shoes and socks come off, it's often for this reason. It takes longer, but it gives your child a chance to understand the activity more fully.

- **Taking time**

This is important. Children with MSI get so little information that they cannot afford to lose any more. Once you have established a routine, it is important for your child to recognise each different part of the activity. It can be difficult to maintain this, but if you can allow yourself extra time, 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 the place of your child. 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.



Interaction and communication

When we think of communication, we tend to think of spoken (or perhaps written or signed) language. A lot of communication, however, is non-verbal and even unintentional. Think how we can judge another person's physical well-being, or willingness to talk to us, from non-verbal, often unintentional signals. Many children with MSI do not use familiar forms of language. All, however, communicate, although understanding their communication as it is developing may take trust, patience and skill.

Some young children with MSI may not yet be aware that what they do can influence what other people do. These children communicate unintentionally (for example, crying when hungry) – and other people interpret the child's actions and give them meaning. Many children who communicate intentionally do so in very definite ways – for example, by pulling an adult towards something they want. Others understand and use symbols, signs or words.

There are two sides to communication: understanding other people, and expressing ourselves. Understanding comes before expression. A child will not be able to ask for a drink, for example, unless they understand what a drink is and that another person can provide it. Everything that happens to your child needs to be as understandable to them as possible. Using consistent routines will help babies and toddlers recognise activities. Using cues to signal what will happen next will help the child to anticipate things. Cues can make use of any sensory channel available. They may be objects, sounds, smells, places, movements and/or pictures. They may occur naturally (for example, the smell of cooking and the sounds of saucepans and crockery) or be deliberately introduced (for example, songs associated with particular activities).

The most important thing in communicating with children with MSI is to follow the child's lead and respond to any signals they give. Even if you are not sure what the child means, make the best guess you can and react. The more your child realises that other people respond to their communication, the more motivated and skilled they will become.

Sensory development

Most children with MSI have some useful sight and/or hearing, but they will 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. They 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. Many children with MSI have fluctuating (varying) levels of sight and/or hearing, so one day they may see an object, 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. Many are very slow to learn the skills associated with seeing and hearing – for example, watching an object as it moves. None of this is surprising, given the challenges that your child is experiencing, but given time and a consistent approach, skills do develop.

Playing, talking or singing with your child held very close to you (on your lap, for example) is an excellent way to help them make sense of what they see and hear. Your voice and appearance will give good-quality information, because you are so near to your child's ears and eyes. Irrelevant background sights or sounds will be at least partly blocked out by your closeness. Your closeness will also help your child to feel secure, and give them extra information through touch, smell and the warmth of your body.



Settling down

Understanding your child's behaviour

A very important part of caring for babies and 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.

Their surroundings and the behaviour of people around them affect children with MSI, just like the rest of us. Exploring the environment is more tiring and more stressful for children with multi-sensory impairment than for sighted hearing people, so they will be more affected by conditions such as hunger, tiredness or pain, or cluttered, noisy or unfamiliar surroundings. Knowing the things that affect your child the most will help you decide on changes in their surroundings or in the behaviour of people working with them.

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. Below are some ideas provided by other parents and professionals related to four key areas: sleeping, eating, personal care and playing.

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 causes:

- the concept of day and night may not be established, particularly if the child has 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. Periods when they are asked to look and/or listen should be kept short in the early stages (10 minutes or less).
- Look at your child's bedroom. Try to make sure it's 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 are 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 the 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

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 and catch up on your sleep.



Feeding and eating

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.

Feeding difficulties can be due to health problems such as:

- physical problems with the 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.

Problems may also stem from a lack of opportunity to play with food and practise eating like other infants do. Because 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 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 the difficulties. This may help in deciding what to do. Other parents say they can respond more calmly if they understand why their child is responding 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 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 are being given.
- 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 the food.
- Support your child in learning to feed themselves as they get older – for example, by helping them load the spoon and then let them put it on their mouth. It may take a little time before the child is 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 lavatory. 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, can learn to co-operate in these routines.

Try to 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.
- 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.

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. Sometimes this is called **tactile defensiveness**.

Here are some approaches 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 they are comfortably positioned and as relaxed as possible.



- 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 toleration of touch. An ideal time for these types of games would be after a bath, when a massage session could also be incorporated.
- Offer opportunities for your child to play with food. Children who are developing normally have lots of opportunities to experiment and play with their food and this is a precursor to interacting with other substances such as paint, playdough and clay. Children with MSI, in contrast, may always be fed by an adult. Playing with food substances, such as yoghurt or custard, allows children to explore through vision, touch, smell and taste at their own pace and away from the pressures of mealtimes. In this way, children can learn about the properties of substances and how they change.
- Choose toys that suit your child’s needs. There is a range of specialist equipment and toys designed to meet the needs of children with MSI that you will see in schools and nurseries, like bubble tubes and fibre-optic cables. But toys do not need to cost a lot of money – everyday objects may be better than toys, but always check for safety. Children can find ordinary items lots of fun to look at and play with, for example:
 - different types of brushes
 - textured fabrics
 - torches, preferably in different colours
 - a washing-up bowl half-filled with warm water.

Some parent support newsletters include good ideas for making simple, effective and stimulating toys.

Equipment and environment

Making small changes to 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.

- 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.
- 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 – if this is possible!
- If you are 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 remaining hearing.
- 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, which can be used to help recognition – on toys, to mark possessions and places, on walls and underfoot.
- Be aware of smells and air currents that might help your child to recognise places and activities.



Think about the information your child receives from their surroundings during particular activities. What information is irrelevant or distracting – could it be removed or lessened? What information is relevant and helpful – could it be improved?

However, this is your home and it's a shared space for everyone.

It's important that the rest of the family isn't left out of decisions about how space is used.

Spectacles and hearing aids

Whether glasses and 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 and hearing. However, that does not mean they will automatically see or hear everything.

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 the deaf](#) about how to build up tolerance. Hearing aids, in particular, may be more useful in some situations than others – most hearing aids will make **all** sounds louder, so when there is a lot of background noise (for example, on a busy road) they may not be helpful. If you understand how hearing aids work, you will be able to support your child better as they start to use them.

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

- the aids have been correctly prescribed, fit well, are working and clean
- the surroundings are unusually noisy, bright or otherwise difficult to hear or see

- your child has an ear infection, an eye infection or other health problem, or whether they are just tired and generally fed up
- your child is comfortably positioned and interested in what is going on.

Be confident about listening to your instincts and to what your child is trying to tell you.

Specialist equipment

A wide range of special equipment may be used with children with MSI. Some of it (such as soft play equipment) is commonly used by children without disabilities, although for children with MSI it might be used rather differently. Other equipment is designed especially for children with complex needs. Resonance boards, for example, are raised plywood platforms on which children lie; any movement the child makes results in vibro-tactile feedback.

Specialist teachers of children with multi-sensory impairments can advise parents about the value of particular types of equipment for their child.



Thinking about social care and education

Early intervention

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 special educational 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.

Social Care for Deafblind Children and Adults - Section 7 guidance

There is help available for children who are deafblind to enable them and their family to take part in normal community activities. This entitlement comes from statutory guidance called *Social Care for Deafblind Children and Adults* issued under Section 7 of the Local Authority Social Services Act (1970). The guidance says that local social services departments must assess every deafblind child in their area for services and then provide what that child needs, including one-to-one support, perhaps through an *intervenor*, if appropriate. Support workers have to be specifically trained, so you can be confident that your child is safe and receiving high-quality support.

The kind of support that social services departments deliver could be in your home (allowing you to have some time to yourself to do other things) or in the local community – for example, taking your child out to local children’s activities.

Having an assessment for these social and community-based activities will not adversely affect your child’s educational support. You don’t have to choose – you are 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.

Many families report the demoralising effect of having constantly to repeat the catalogue of their child’s disabilities and needs to each doctor, nurse, therapist and teacher. Parents comment that they always have to say what their child cannot do rather than emphasising the things that their child can do.

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. Ask the people who work with you about this pack or look at the back of this booklet to find out more.





Choosing a nursery or other early years setting

Children with MSI may be educated in a range of settings in the early stages when they first attend a nursery, playgroup or early years setting.

Increasing numbers of children with special educational needs are educated in mainstream nurseries or mainstream schools with support. This policy of inclusion aims to combat discrimination against people with disabilities and to include them fully in society. Inclusion for children with MSI sometimes means they are educated with children with other disabilities (for example, single sensory impairments), whose communication systems are similar to theirs.

For children with MSI, successful inclusion depends on their needs, abilities, interests and personality, the resources provided (particularly staffing levels and staff training) and the attitudes of staff and other pupils.

Choosing a school or nursery for your child is a very personal decision. You might want to think about some of the following points. Some of the questions clearly have right or wrong answers, but many do not – they depend upon your preferences and what you want for your child.

- Do the staff appear to be interested in your child as an individual?
Are they interested in what you can tell them about your child?
- How does home–school liaison work? How easily can you visit?
- 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 school 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? 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?
- Are there local community links, for example with other nurseries or schools? Are there any other inclusive activities? Will your child be as fully included in society as is compatible with meeting their needs?
- Do you feel comfortable and welcome?
- If your child has to travel a long way to school, how will the LEA support that?



Read more about
Sense on the
next page

Who can help?

Sources of help and support

There are many sources of help available to families with children with MSI. Professional help may come from local specialists or perhaps from a voluntary organisation. In the early years there may be contact with [health visitors](#), [GPs](#) and other medical staff, teachers and perhaps therapists such as [physiotherapists](#). A considerable number of professionals may be involved.

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

Minicom: 020 7608 8702

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 Family and Education Advisory 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. The Sense Family Network provides 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.

11–13 Clifton Terrace
Finsbury Park
London N4 3SR

Tel: 020 7272 7774
Textphone: 020 7272 9648
Fax: 020 7272 6012

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



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 in simple terms what different professionals do.

Advisory teacher

An **advisory teacher** is a teacher, usually with additional training in a particular specialism, who advises schools and families on educational approaches. Some advisory teachers visit families with pre-school age children in their homes.

Audiology technician

An **audiology technician** carries out hearing tests and fits and monitors hearing aids.

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.

Dietician

A **dietician** is a health professional who can advise on diet-related matters.

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** is a qualified teacher who has additional training as a psychologist. 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.

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.

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.

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.

Music therapist

A **music therapist** helps children to learn and express themselves through music.



Nursery nurse

Someone trained in, and able to support, the early stages of child development. They usually work in nurseries and schools. (They are not medical nurses.)

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.

Occupational therapist

An **occupational therapist** helps children improve their developmental function by therapeutic techniques, environmental adaptations and the use of specialist equipment.

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).

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 helping people with movement problems. 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 education authority.

Qualified teacher of children with hearing impairments (Teacher of the deaf)

This is a teacher with additional training (recognised by the Department for Education and Skills) in the education of children with hearing impairments.

Qualified teacher of children with multi-sensory impairments

This is a teacher with additional training (recognised by the Department for Education and Skills) in the education of children with multi-sensory impairments.

Qualified teacher of children with visual impairments

This is a teacher with additional training (recognised by the Department for Education and Skills) in the education of children with visual impairments.

SENCO

A **SENCO** is the Special Educational Needs Co-ordinator, based in a school, who is responsible for ensuring that all children with statements of special educational needs are receiving the provision outlined on their statement.

School nurse

A **school nurse** is a medical nurse based in a school who provides support for children's medical needs.



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 equipment 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.

Speech and language therapist

A **speech and language therapist** is a health professional specialising in communication development and disorders (and associated eating and swallowing difficulties).

Support groups and useful organisations

Advisory Centre for Education (ACE)

Advisory Centre for Education Ltd
1c Aberdeen Studios
22 Highbury Grove
London N5 2DQ

General advice line: 0808 800 5793

Web: www.ace-ed.org.uk

Carers UK

20–25 Glasshouse Yard
London EC1A 4JT

Tel: 020 7490 8818

Carers Helpline: 0808 808 7777

Fax: 020 7490 8824

Email: info@ukcarers.org

Web: www.carersonline.org.uk

CHARGE Family Support Group

Initial contact for new families:

Hannah Levey

82 Gwendolen Avenue

London E13 ORD

Tel: 020 8552 6961

Email (Chairperson): cajtthomas@btinternet.com

Web: www.widerworld.co.uk/charge



Citizens Advice

Myddelton House
115–123 Pentonville Road
London N1 9LZ

The Citizens Advice Bureaux Service offers free, confidential, impartial and independent advice.

Tel: 020 7833 2181

Fax: 020 7833 4371

Web: www.adviceguide.org.uk
www.Citizensadvice.org.uk
(to search for your local Citizens Advice Bureau)

Crossroads – Caring for Carers

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

DELTA (Deaf Education Through Listening and Talking)

PO Box 20
Haverhill
Suffolk CB9 7BD

Tel/Fax office: 01440 783 689

Email: enquiries@deafeducation.org.uk

Web: www.deafeducation.org.uk

Genetic Interest Group

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

National Centre
123 Golden Lane
London EC1Y 0RT

Tel: 020 7454 0454

Fax: 020 7608 3254

Email: help@mencap.org.uk

Web: www.mencap.org.uk

Learning Disability Freephone Helpline: 0808 808 1111

Learning Disability Freephone Minicom Helpline: 0808 808 8181

The National Deaf Children's Society

15 Dufferin Street
London EC1Y 8UR

Helpline: 0808 800 8880

Email: helpline@ndcs.org.uk

Web: www.ndcs.org.uk



Princess Royal Trust for Carers

142 Minories
London EC3N 1LB

Tel: 020 7480 7788
Fax: 020 7481 4729

Email: info@carers.org

Royal National Institute of the Blind

105 Judd Street
London WC1H 9NE

Helpline: 0845 766 9999
Fax: 020 7388 2034

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

Royal National Institute for Deaf People

19–23 Featherstone Street
London EC1Y 8SL

Helpline: 0808 808 0123
Textphone Helpline: 0808 808 9000
Fax: 020 7296 8199

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

Information for parents
Multi-sensory impairment

Scope

6 Market Road
London N7 9PW

Cerebral Palsy Helpline: 0808 800 3333

Cerebral Palsy Helpline Fax: 01908 321 051

Helpline address:

PO Box 833

Milton Keynes MK12 5NY

Helpline email: cphelpline@scope.org.uk

Web: www.scope.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 guarantees of accuracy or lack of bias. The following sites are some of the more specialist and well-supported.

[Contact a Family \(www.cafamily.org.uk\)](http://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 \(www.tr.wou.edu/dblink\)](http://www.tr.wou.edu/dblink) 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 \(NDCS\) website \(www.ndcs.org.uk\)](http://www.ndcs.org.uk) provides information about childhood deafness.

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

The [Royal National Institute of the Blind \(www.rnib.org.uk\)](http://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 \(www.sense.org.uk\)](http://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 \(www.scope.org.uk\)](http://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 \(www.sensescotland.org.uk\)](http://www.sensescotland.org.uk) website has information and a range of links particularly to Scottish organisations.

Information for parents

Multi-sensory impairment

The [Scottish Sensory Centre \(www.ssc.mhie.ac.uk\)](http://www.ssc.mhie.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.



Early Support is a Government funded programme involving the Department for Education and Skills, Sure Start and the Department of Health. The purpose of the programme is to improve the delivery of services to disabled children under three and their families. It promotes service development in partnership with health, education and social services, service users and organisations in the voluntary sector. For more information, visit www.earllysupport.org.uk

Early Support is putting into practice the principles outlined in the Government guidance document *Together from the Start* which was published in May 2003. The guidance recognises that where children have special needs and disabilities, it is important that these are identified at an early stage and that identification leads directly to effective early intervention and support for families and children.

This booklet is one in a series produced by **Early Support** in response to requests from parents and voluntary organisations for better information for parents. The programme has produced booklets about a number of disabilities or known conditions and expects to develop more as the programme progresses. The following titles are currently available:

Autistic spectrum disorders (12)	Cerebral palsy (10)
Learning disabilities (15)	Down's syndrome (13)
If your child has a rare condition (18)	Multi-sensory impairment (9)
Speech and language difficulties (14)	Visual impairment (8)
When your child has no diagnosis (16)	Deafness (11)

Copies of these booklets can be obtained from:

DfES Publications
PO Box 5050, Sherwood Park,
Annesley, Nottingham NG15 0DJ
Tel: 0845 602 2260 Fax: 0845 603 3360
Textphone: 0845 605 5560 Email: dfes@prolog.uk.com

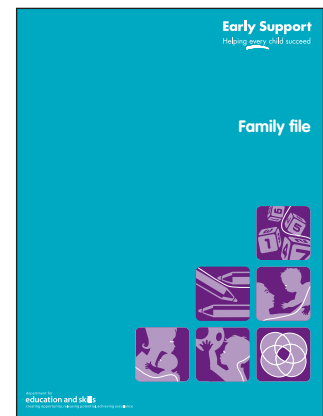
Please quote the appropriate reference number.

Early Support has also produced a **Family Pack**, which supports families through the first years of their children's lives. The Pack contains background information about the services you may need, the help you are entitled to and a **Family File** designed to help co-ordinate any support being provided for your family. They are resources that other families have said would make a difference. If you and your child are receiving regular support from a professional or range of professionals, please feel free to ask them about the **Early Support Family Pack**, which may help and which is available free of charge.

Early Support would like to thank all the parents and families involved in the production of these resources.

Early Support would also like to thank **Sense** for their help in writing, consulting upon and producing this resource.

Sense is the national charity that supports and campaigns for children and adults who are deafblind and multi-sensory-impaired. We 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 national network and local branches. We also provide 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:
DfES Publications
PO Box 5050
Sherwood Park
Annesley
Nottingham NG15 0DJ
Tel: 0845 602 2260
Fax: 0845 603 3360
Textphone: 0845 605 5560
Email: dfes@prolog.uk.com

Please quote ref: ESPP9

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www.earlysupport.org.uk

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