

# Early Support

for children, young people and families

## Information about multi-sensory impairment



## About this resource

This is an information resource for parent carers who have 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 impairments with both sight and hearing.

In this resource you will find information on:

- What is multi-sensory impairment?
- How this will affect you and your child
- Where to go for further support and information

This resource was developed by **Sense** for Early Support.

### Early Support

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

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

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

To find out more about Early Support, please visit [www.ncb.org.uk/earllysupport](http://www.ncb.org.uk/earllysupport)

Where a word or phrase appears in colour, **like this**, it means you can either; look them up in the **Glossary** at the back of the resource; that the contact details for the organisation or agency identified are listed in the **Useful contacts and websites** section; or that you can find out more in the **Who can help** section.

### Explanation of the term parent carer

Throughout this resource the term 'parent carer' is used. It means any person with parental responsibility for a child or young person with special educational needs or disability. It is intended as an inclusive term that can cover foster carers, adoptive parents and other family members.

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## Multi-sensory impairment

### What is multi-sensory impairment?

Children and young people with multi-sensory impairment (MSI) 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 and young people 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 can see or hear, especially if they have other problems.

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

A huge range of conditions can cause MSI. There's no single or main cause. Diagnosis can take time and many parent carers find this very difficult. Understanding how their child's condition might progress in the future is very important. Find out more information here: [www.sense.org.uk/a-z-of-conditions](http://www.sense.org.uk/a-z-of-conditions)

Many of the conditions causing MSI are extremely rare. Local medical staff may have little experience or knowledge of your child's condition and you may be referred to a regional or national centre where a team of specialists can help make the diagnosis and offer on-going support. More information can be found at [Sense](#) or [Contact a Family](#). Every child has different, individual needs and children with the same diagnosis vary enormously in their development 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 development and their hopes for the future.

Practitioners 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.

## How we use our senses

Our experience of the world, our 'reality', comes through our senses. People with hearing and/or visual impairments 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 all 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 more developed sense to keep in contact with the world around them. Children and young people with multi-sensory impairment (MSI), however, cannot use either of the distance senses to compensate. In addition, many children and young people 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 and young people with MSI need to get as much information as possible from any useful sight and hearing they have and from their other senses. For many children and young people, touch can provide a means of learning about the world and a means of communicating. Some children and young people with MSI become very skilled in using the sense of smell, for example, and use it to identify people and places. Some recognise movement around them because of something as subtle as changes in air pressure on their skin.

## What does multi-sensory impairment mean for my child?

We normally get most of our information about the world around us through sight and hearing, so multi-sensory impairment (MSI) makes a significant difference to children and young people'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 and young people with MSI need extra help with the following areas:

- Children and young people 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. They may be impeded in learning 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 and young people with MSI do develop close relationships, especially with their family, like any other child or young person. Initially, children with MSI may seem unresponsive to parent carers because they don't see or hear the smiles, looks and speech most babies respond to. They may 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 and young people with MSI cannot learn by watching what happens around them, as sighted hearing children do. MSI makes children and young people learn more gradually, because they get information that is of poorer quality. This does not mean that they necessarily have learning difficulties/impairments. 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 and young people with MSI can and do learn effectively.
- Children and young people with MSI often take longer to realise that their actions affect what happens to them. This means that they take longer 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 and young people to understand and learn to control them. MSI reduces children and young people's ability to anticipate events – to know what is likely to happen next – and this makes exploration harder. Children and young people with MSI often have difficulties generalising skills and knowledge from one situation to another, because they don't see the similarities and differences between different situations.

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 them.



## Diagnosis and support

Multi-sensory impairment (MSI) arises from a wide range of causes. Children may be born with MSI or acquire it following illness or injury. Or they may have MSI as the result of a progressive condition, the impact of which is felt in later childhood. In every case, in the early days, it's often difficult for doctors to make a diagnosis and for other practitioners to get a clear picture of the child's abilities and needs. This can be very hard to come to terms with.

### At birth

*'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.'*

*'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, parent carers 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 – practitioners – are the only ones who know how to care for your baby. This is not true.

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

### In childhood or adolescence

A child or young person who loses their sight and hearing after they have developed language in their early years is said to have an **acquired loss**.

This may arise from illness, like meningitis or an accident.

Or it could be related to a specific genetic condition from birth like **Usher syndrome**. The age of onset, the extent and the progression of sight, vision and balance problems varies with each individual.

For children and young people who *become* multi-sensory impaired getting the right support after diagnosis is most important. Adjusting emotionally to change is a huge challenge for all the family as communication and other day to day activities are all affected.

## 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, scared, 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 parent carers to feel lonely and isolated. You, and other family members, may feel overwhelmed by lack of experience of having a child with additional 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.

### **A later diagnosis**

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 child'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.

### **In childhood or adolescence – the grief of loss and change**

If your child has become multi-sensory-impaired through illness or accident, the sense of shock and fear is often delayed while you help in their recovery. You may feel that your child has changed in "an instant" and the future seems overwhelming. Coming to terms with a new situation is not only emotionally exhausting but creates practical issues that you will never have had to consider before.

If your child has a condition which includes degenerating hearing/sight the changes will often be gradual over time. You may have known about, and anticipated this situation as your child has been growing up, but this may not lessen the sense of loss and upset you feel when it begins to happen.

Every family must prepare for a very steep learning curve. Having access to the right information and support is crucial. Harness the kindness of friends and family to help you find the strength to move forward and expect support from teachers and other professionals.

*'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 parent carers 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 Multi-sensory impairment (MSI), this initial 'getting to know you' time may be interrupted by the baby's medical needs. The general 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, and other people's voices. Just knowing this can help you to find other ways to make a connection to start the relationship developing.

The following tips, also included in the later section of the booklet *Developing the senses* may help you to develop your relationship with your baby.

- Play, talk or sing with your child held very close to you – for example, on your lap with a small child or supported by you on the floor as your child gets older. 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.

## Looking after yourselves

Remember your own needs. This can be hard to do when your baby/ young child 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 and so on.

- 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. Participate in your cultural activities and celebrations. 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 practitioners you meet, or contact a voluntary organization, such as [Sense](#).

Remember that practitioners are there to help you, not just your child.

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

## General information for all families

### Everyday life

Children and young people with multi-sensory impairment (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 and young people 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 carers and practitioners related to five key areas: sleeping, eating, personal care, moving around and making your home environment child-friendly.

### Making sense of the world

Children with multi-sensory impairment (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.

Parent 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. 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 consistency 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, so shoes and socks may come off. It takes longer if you encourage your child to participate like this, but it gives them a better chance to understand what's happening.
- 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.

## Developing the senses

Most children with MSI have some useful sight and/or hearing and families can help them 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 children with MSI 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 senses:

- Play, talk or sing with your child held very close to you – for example, on your lap with a small child or supported by you on the floor as your child gets older. 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, hearing aids and having a cochlear implant

### 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 MSI, aids for eyes or ears will almost certainly help but 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.

### **A cochlear implant**

A cochlear implant can make a big difference to some children with MSI. It can provide access to environmental sounds and spoken language. With appropriate post cochlear implant care and support, children have the opportunity to develop a much greater appreciation of the "sound" world around them and, for some, the chance to develop spoken language. Find out more information here: [www.earfoundation.org.uk/cochlear-implants](http://www.earfoundation.org.uk/cochlear-implants)

A series of medical assessments can establish how suitable an infant or child is for this procedure as not every child will benefit.

### **Playing and leisure**

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. 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. Many children who develop atypically have lots of opportunities to experiment and play with their food and this leads to interacting with other substances like paint, play dough 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.

### **Children and young people**

Activities should be fun, age-appropriate and based upon the choices of the individual. Some of the games your child has always enjoyed can be adapted using more age appropriate toys or equipment. For example;

- Tricycle or dual bikes get the family exercising.
- Computer screen and interactive applications can support learning while having fun.
- Ipad or tablet computers can be a communication aid.
- Enjoying music – using headphones on a personal player encourages choice making.

- Having a regular job around the house can help with independence skills.
- Bowling, traditional cultural games, dancing, swimming, and playing video games are all things that can be done as a family or with other young people.

### **The question “is it safe” comes up every time...**

If a child or young person starts a new physical activity caution must be taken. If there is a heart condition, a potential for retinal detachment, tubes in the ears, or a shunt, the doctor needs to be consulted. But remember, that almost any activity can be adapted for individual needs and you will be an expert very soon.

## **Sleeping**

Children with multi-sensory impairment (MSI) may not easily establish regular patterns of sleep and wakefulness. This can be particularly hard for parent 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 sleep 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 with few distractions.
- Make sure your child has opportunities during the day for both exercise and rest. Get them outdoors as much as possible – natural daylight helps to set our body clocks.
- 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 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 baby monitor so you can observe your child without having to disturb them.
- Using this or a similar routine with older children too means that they can spend time away, with grandparents or other family members or on a holiday with other

children and as long as the routine is understood by others, settling down to sleep shouldn't be an issue.

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

Remember that you 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 on a regular basis can give you time for yourself, including time to catch up on your own sleep.

For more information please see the Early Support information resources on **Sleep** at [www.ncb.org.uk/early-support/resources](http://www.ncb.org.uk/early-support/resources).

## Eating and drinking

Many children with Multi-sensory impairment (MSI) 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 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.

Or

- A lack of opportunity to play or explore with food and practice eating in infancy – like some others do.
- A poor sense of smell - smell often motivates the desire to eat.

## Children and young people

By school age, some children will still need help and encouragement. Some may become "fixed" on certain foods and refuse other offers. This can make mealtimes stressful and eating with friends, or at school, harder to manage. Ask for advice about how to introduce new foods.

Others will enjoy food and eat excessively if given a choice.

If your child has a particular diagnosed syndrome or condition you might want to check

whether a physical problem or behaviour 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 advise you.

### **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 carers 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 into what is about to happen. Use a bib or spoon or some other resource that is culturally appropriate to your family 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 are 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 encourage 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 eat more independently as he or she gets older – for example, by helping them load the spoon or other culturally appropriate means of eating and then letting them put it in 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 needs, 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 MSI 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 using 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 stop them removing their nappy. For older children, dungaree-style sleep suits can be made (the arms and neck need to be quite high).
- For **older children and young people** routine is still important. Bathing or showering daily and cleaning teeth twice daily are essential. This is one of the key planks on the road to successful adulthood.
- Adult products for bathing and shaving may be offered but may not be chosen over those that are already familiar.
- Before puberty, for boys and girls, ways of sharing information about what will happen, need to be considered and a practical routine established. The school should be able to help you with this.
- 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 often take longer 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 impairments or challenges. 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 while feeling secure because they are close to you. Slings and backpacks are useful indoors as well as out.
- 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.
- 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 parent carers 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 different textures and objects can be placed within the child's reach, for instance on the sides and roof, so that any movement brings the child into contact with something interesting. Find out more information on 'Little Rooms' here: [www.deafblindinternational.org/review1\\_q.html](http://www.deafblindinternational.org/review1_q.html)
- 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. As they get older they may use a frame instead.

- 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.
- As your child develops a **mobility specialist** should be involved to encourage skill and confident movement – including exploring outside and going to school.

## 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 (i.e. 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.

These ideas are also useful to consider when your child goes to school.



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 so that any movement gives them vibro-tactile feedback.

## A range of professional practitioners may be involved with your child

Children with Multi-sensory impairment (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 co-ordinate the way they work to ease the pressure on families e.g. hospital appointments and therapy visits to the home in the early years and to school later on.

In many areas **key workers** 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 away. Ask questions about anything you don't understand or disagree with.

It is important that you tell everyone concerned with your child 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.

Try not to feel demoralized when every new doctor, nurse, therapist and teacher that you meet asks you to repeat a list of your child's difficulties. Make a communication passport about your child and ask them to read it through. It's a very simple person friendly way of summarising aspects of child's life and emphasizing the best way to say hello using the child's preferred communication method. This won't solve every problem about sharing information, but it can help! Find out more information here:

[www.communicationpassports.org.uk/Home](http://www.communicationpassports.org.uk/Home)



## Meeting other families

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. **Sense** has a specialist service for children and families, regional branches and a national family network. **Sense** may be able to advise you on the possibility of accessing a local parent and toddlers group or similar. Find out more information here: [www.sense.org.uk/content/services-children-and-young-people](http://www.sense.org.uk/content/services-children-and-young-people)

**Contact a Family** is an umbrella organisation of family support groups that focus on very rare conditions like **CHARGE syndrome**, **Usher syndrome**, **Alström syndrome** and many others.

Parent carers can also meet other families via the internet. There are a number of networks that put families in touch with counterparts across the world for discussion and sharing experiences.

### Children and young people getting together

**Sense** runs holidays for children, young people and young adults. It also arranges events for young people, with CHARGE syndrome or Usher, for example, to come together, and meet others who may be facing similar issues in school, college or the outside world. For this older group having a chance to share concerns *without* parents carers or teachers present, but with people they can trust, is a great opportunity for any young person.

Getting out locally, even to see school-friends is hard to organise because of communication and mobility issues. By using **social care guidance**, communication or other support can be funded through the local authority to give children, young people and adults the chance to get out into the community.

## Social care for multi-sensory-impaired children

It is extremely difficult for children and young people who have Multi-sensory impairment (MSI) and their family to take part in ordinary community activities either together or separately.

Help is at hand. It comes from statutory guidance called Social Care for Deafblind Children and Adults issued under Section 7 of the Local Authority Social Services Act. Find out more information here:

[www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/LocalAuthorityCirculars/DH\\_101114](http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/LocalAuthorityCirculars/DH_101114)

The guidance says that local social services departments or children's departments must assess every MSI child in their area for services and then provide what that child needs,

including one-to-one support, if needed, perhaps through an **intervenor**. For more information about the role of an **intervenor** please view this You Tube film:

[www.youtube.com/watch?v=oC1bJBwydhk](http://www.youtube.com/watch?v=oC1bJBwydhk)

The kind of support that social services departments deliver could be in your home or in the community – for example taking your child out to an activity like swimming or riding or to engage in activities that support their ethnic or other cultural identities or to a football game or a youth club.

Having an assessment for these social, cultural 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.

## Early Years

### Getting started

*“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 Multi-sensory impairment (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 parent carers and other family members.

#### **Here are some tips that may help:**

- Children with multi-sensory impairment (MSI) 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 and support 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 practitioners 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.
- Any pets in the house are also part of the family and need to be introduced to your child carefully. 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 multi-sensory impairment (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 parent carers!

For more information please see the Early Support information resource on [Behaviour](https://www.ncb.org.uk/early-support/resources) at [www.ncb.org.uk/early-support/resources](https://www.ncb.org.uk/early-support/resources).

## Interacting and communication

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 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 try to communicate.

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

- 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.
- 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 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. You may also have other rhymes from your own cultural traditions that you could use too.
- 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. 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.

Some children with MSI communicate by body movements, facial expression, sound or by pushing or pulling an adult towards something they want.

### **Older children**

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 **total communication** approach.

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.

These communication systems will be used in school and they might also be used in early years settings or out of school services as well.

## School Years

### Getting started

*"I hadn't realised how much I would have to learn. It's like a new world"*

If a child has a learning difficulty/impairment which calls for special educational provision to be made for them, they are termed as having 'special educational needs' (SEN) under SEN statutory definitions.

### What kind of support does your child need?

So, for a child with Multi-sensory impairment (MSI) starting in the school system, a statutory process is in place to make sure the support they require to succeed is known. It begins with an assessment which provides specialist information about a child's needs. Find out more information here:

[www.education.gov.uk/publications/eOrderingDownload/00639-2008.pdf](http://www.education.gov.uk/publications/eOrderingDownload/00639-2008.pdf)

From this information a plan is developed to provide the right support to the child. This called a Statement of Special Educational Need. Statements of special educational needs say what your child's needs are. They are reviewed every year. Parent carers are full participants in this process and as you know your child best. Find out more information here: [www.gov.uk/children-with-special-educational-needs/statements](http://www.gov.uk/children-with-special-educational-needs/statements)

There is a lot to absorb about this process, so click through to the full details.

### Who makes provision?

There are services dealing with education in your local authority that can provide advice and support throughout your child's school career. They play a key role in making sure you are fully informed to participate in decisions that affect your child's education and this includes the schools you might choose.

They will provide information about all the schools and services in your locality that may be useful to a child with additional needs. This should include local schools, including any that have specific expertise with sensory impaired pupils. Some of these may be regional or national schools. This information will include schools that are not directly run and funded by the local authority, but by central government. Some of these are called **Free Schools** and **Academy Schools**.

You can look online at the school websites and their latest Ofsted inspection report before you make any decisions to visit and discuss admission.

## Getting it right for children who are multi-sensory-impaired

Some particular issues are most important when thinking about the education of children with multi-sensory impairment (MSI).

Hearing and sight are our primary means of getting information from the environment, particularly beyond arms reach. MSI creates enormous disadvantage for children in terms of knowing where they are and what is happening around them. Any degree of combined sight and hearing impairment can create this disadvantage – impairments that may range from mild to profound, may fluctuate or cause consistent loss, and can affect the reception and/ processing of sensory information. Additional impairments often accompany MSI – for example touch, balance or smell.

Mainstream approaches to education depend on teaching and learning taking place through the main senses of sight and hearing. Children who have multi-sensory impairments have unique educational needs because of their difficulties in accessing education in this way.

Whether a child had a **congenital loss**, **acquired loss** or **degenerative condition**, communication is the key to successful learning. Developing an effective communication system to access information is essential for each child to make the most of academic and social opportunities.

And this is true across a school career; right from the start, and regardless of age group.

## The right support for your child

The assessment, and the Statement that follows, will establish what kind of human support and physical adaptations will be required to give each child a good start in school.

Prior to entry to school (nursery, primary, secondary) there should be evidence of local authority planning, which involves some or all of these suggestions:

- Opportunities for the child and family to familiarise themselves with the school
- In- service training for the whole staff on MSI awareness; the specific needs of the child/young person, specific teaching and learning strategies.
- Specialist advice from an advisory teacher (**Qualified Teacher of MSI VI HI**) often working with a trained communication support worker, like an **intervenor** or **sign language interpreter** who is based with the child in the school.
- Support from therapists.
- A differentiated, or specialist curriculum that includes sensory awareness and skills, communication, mobility, independence skills.
- A physically adapted school environment.
- Aids and equipment appropriate to support learning.



- Equality Named Coordinator/Equality Coordinator support to ensure that your child's equalities needs are planned for and met.

## Finding a pre-school setting

Children with MSI may be educated in a range of settings in the early stages when they first attend a nursery, playgroup, childminder or other early years setting. They may be part-time or fulltime – each child will be different.

For parent carers any setting should feel **positive and welcoming**. Questions, from both sides, should be encouraged.

### Ask questions!

Choosing a pre-school, childminder or nursery for your child is a very personal decision and you might want to think about some of the following points. 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 their first meeting?
- What resources does the setting have? Ask about qualified specialist teachers, SENCO and ENCO in put, 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?
- Which staff will work with your child?
- How much training have they had in multi-sensory impairment? If your child will be supported one-to-one, is this by a trained **intervenor**?
- Are there any other children with similar needs to your child?
- Have all staff had equalities training? How are staff values and attitudes assessed in regard to disability equality?
- How will your child communicate with staff, peers and other people?
- Is the physical environment appropriate?

## Finding a primary school

You may already know about your local primary schools and have a preference in mind. You may want your child to attend with siblings or friends or to join the children who have been at pre-school or play group or in a child minding setting with them.

Look at all the options on offer: as well as your local school there may be a school with an integral specialist unit for hearing or visually impaired children or a special school for children with complex needs. Either of these may suit your child better.

Whichever you choose it should be because the learning environment, which includes the people, places, positive and affirming messages, objects and activities are right for your child.

### Ask questions!

When you visit the schools, remember the things that your child will need and think about the following core areas

- Will the whole staff have staff development time to understand MSI and your child's particular needs?
- Will the school have regular specialist advice from an advisory teacher (Qualified Teacher of MSI)?
- Will they have a trained communication support worker, like an **intervenor** or **sign language interpreter** based with the child in the school?
- Are they confident about being able to deliver a differentiated, or specialist curriculum that includes sensory awareness and skills, communication, mobility, independence skills?
- Would the school environment need much adaptation?
- Is there room for the communication aids and other equipment required? If your child uses a wheelchair are all areas accessible?
- What would the transport issues involve?
- Does the school have a SENCO and an ENCO?
- Does the school give due regard to equality requirements? How do they do this?
- Could he/she be happy here?

Each child's needs are different but every child with MSI should have support from visiting teachers that are specially qualified teachers of sensory impairment. These teachers understand the particular requirements of children with hearing, vision or multi-sensory impairment

Ask questions about the physical environment and about how it can be adapted. Think about the things that are would be relevant and helpful, and how they could be tailored to support your child. Schools will welcome your feedback. Find out more information here:

[www.deafblindinternational.org/review1\\_q.html](http://www.deafblindinternational.org/review1_q.html)

Look back at the questions suggested for early years settings and use them if you wish. As before, choosing a school for your child is a very personal decision. You need to feel you have sufficient information to give you the confidence to choose.

## Moving on to secondary school

*“We knew about our local school because our other son was there. It made us think more carefully about what we wanted”*

The move from primary to secondary school feels like a huge leap for most children and those with MSI are no exception.

Your decision this time will be informed by progress achieved at the primary school. You will know so much more clearly about your child’s abilities; level, style and pace of learning, physical limitations and preferred mode of communication. And you will have staff, friends and your child to join you in making the choice.

### Mainstream

Secondary schools are much, much larger and the style of teaching and learning becomes a lot more formal. They operate a strict timetable focusing on distinct subjects being taught by a series of different teachers. This means that pupils move from classroom to classroom, engage with a variety of teachers and have to get used to an academic approach.

### Mainstream with specialist resource base

In your local authority there may be a mainstream secondary school that has integrated support for sensory impaired pupils. If so, this can provide some continuity, as awareness will be high and specialist staff are based in the school. Pupils spend a lot of time in the mainstream classes (with support) but also have time to focus on their additional sensory needs in a resource base, also in the school. As there will be a cohort of pupils with similar communication needs your child could benefit from of a peer group of sign language users, users of total communication, or Braille users.

### Special(ist) School

Families with children with complex MSI may consider a **specialist school**. Ask to look around. The learning environment must suit your child’s needs and aspirations.

### Non- Maintained Special Schools

There are also some schools, with a national catchment, which specialise in teaching children with sensory impairments. Many of these charitable founded schools pioneered the work with deaf, visually impaired and MSI pupils and offer a residential option.

## Ask questions!

When you visit the schools think about the following core areas

- Will the whole staff have staff development time to understand MSI and your child's particular needs?
- Will the school have regular specialist advice from an advisory teacher (**Qualified Teacher of MSI**)?
- Does the school have SENCO and an ENCO?
- Will they have a trained communication support worker, like an **intervenor or sign language interpreter** based with the child in the school?
- Are they confident about being able to deliver a differentiated, or specialist curriculum that includes sensory awareness and skills, communication, mobility, independence skills?
- Have staff undergone equalities training and assessment for their attitudes and values on disability equality?
- Would the school environment need much adaptation?
- Is there room for the communication aids and other equipment required? If your child uses a wheelchair are all areas accessible?
- How will "skills for life" be taught?
- What would the transport issues involve?
- Could he/she be happy here?

Skills for life are very important and cannot be overlooked. Having coaching to exercise self-determination built into the curriculum while still in secondary school, the better equipped they will be upon leaving and taking on primary responsibility for the direction of their adult lives.

## Assistive technology

Whatever the pupil's ability and whatever school is chosen, young people with sensory impairments have access to a whole array of assistive technology and wireless mechanisms that can improve their access to educational materials and enhance their ability to communicate with teachers and their peers.

For a young people with MSI taking an academic route, for example, the need for access to a large volume of printed material is a reality and a hurdle that needs to be overcome.

Effectively utilising today's technology can increase a pupil's ability to receive, in a timely manner, all of the information presented or made available to other classmates. This provides a real opportunity to truly participate.

Every child and young person can benefit as aids get better and equipment becomes more effective. Many more applications are available to support learning and the presentation can usually be adapted to the individual user.

## Equipment and aids

*“An auxiliary aid includes an auxiliary service and is anything which provides additional support or assistance to a disabled pupil.”*

It's often hard to know everything about the equipment and aids that are available to help a child or young person with MSI but getting the chance to try new things out will give a good idea of what is useful.

Fortunately, schools must take “reasonable steps” to provide auxiliary aids so as to avoid the disadvantage experienced by disabled pupils. This covers lots of things including human support. Examples include:

- A piece of equipment.
- The provision of a sign language interpreter, lip-speaker or deafblind communicator (**intervenor**).
- Extra staff assistance for disabled pupils.
- An electronic or manual note-taking service.
- Induction loop or infra-red broadcast system.
- Videophones.
- Audio-visual fire alarms.

Because MSI is such a complex condition you may need to call on different professionals to 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/services 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/services to help your child play, learn and communicate.

## Home-school communication

Your child may travel to nursery or school in local authority transport, usually a minibus or taxi. Not collecting your child from school makes it harder for you to talk to school staff. There are usually several ways of staying in contact with the school – for example, daily home-school diaries, parent carer evenings, 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.

## Changing schools – making it work

Managing the transition from school to school and then to college and adult life needs careful planning to make it easier for a young person with Multi-sensory impairment (MSI).

Because they get so little reliable information from their residual vision and hearing it will take longer to learn about new people, places and activities. This means that new places may be confusing and frightening for them. The following approaches may help:

- Staff from the new school/college visit the child's or young person's home and/or school before the move.
- Information about the move is shared well before it is planned.
- If there is a new uniform it can be worn in preparation and in connection with the upcoming change.
- Visits are made to the new school/college for slowly increasing periods of time.
- The child's or young person's communication system is embedded so that the same cues for activities, communication modes, ways of explaining what is happening and some of the same routines are adopted.
- The **intervenor** or another familiar adult spends the first few weeks with the young person in the new setting, gradually handing over to new staff.

## If things aren't working in education or social care

It is the ambition of the government and your local authority that every child including those with SEN reaches their full potential in school and can make a successful transition to adulthood and the world of further and higher education, training or work.

However, sometimes you may find that things are not working for your child in the way you want. Your child's progress or happiness may be of concern and, if so, you should speak to the school in the first place to discuss the worries you have. You can work with staff to resolve the situation.

If your concern is about the level of support on your child's statement of needs this is reviewed on an annual basis. No changes can be made to it without consulting you first. If

you disagree with any proposed change you can appeal to special educational needs and disability tribunal. Find out more information here:

[www.justice.gov.uk/tribunals/send/appeals](http://www.justice.gov.uk/tribunals/send/appeals)

If you have concerns about the support for out of school activities that have come through Deafblind Guidance you will also have an opportunity to appeal. Find out more information here:

[www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/LocalAuthorityCirculars/DH\\_101114](http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/LocalAuthorityCirculars/DH_101114)

**Sense** can give advice and practical support.

## Into adulthood

### Getting started

For all young people, adolescence is the preparation for adulthood. During this period each young person changes physically and emotionally; they move from school to college or work: they learn to manage their money and social lives. In time, they will leave home, make their own decisions and choices and begin to enjoy their independence.

For young people with multi-sensory impairment the transition to adulthood is just as complicated. In addition to experiencing all strong feelings that characterises adolescence these young people face particular challenges: finding suitable college courses and developing an independent social life, for example.

This is stressful time for families, as every parent knows.

In particular when:

- A young person has complex needs and will continue to need not only communication support but personal care.
- A young person's condition may be changing, with sight or hearing difficulties becoming more pronounced, thus challenging hopes and dreams for the future.
- A new diagnosis makes planning harder.
- The parent carers begin to wonder what adulthood will bring for the child they nurtured so closely.

### Thinking about the future

Some young people with MSI will know exactly what they would like to do in the future, and some will even have the steps planned to achieving their goals. While still requiring communication support they will feel confident to move forward alongside their peers in school and takes steps into the world outside.

For many others thinking about their future is much harder and a lot more work has to go into considering the options. For young people using a range of support services there is a general acknowledgement that in moving away from school they will be leaving many of the familiar places and people that they feel comfortable with. Too often, the discussion still focuses on how to move to adult services, rather than becoming an adult!

Fortunately, for all the young people with MSI, there is a **statutory process** in place to ensure that each young person receives the support *they* deserve in planning for their future.



## Transitional planning

The process is called **transition planning** and it focuses on the young person. Its function is to identify the young person's needs and wishes and then develop an individual plan for their future using a range of agencies and services, such as social services, health, further/ higher education, housing, leisure and employment. This is called a **person-centred plan** (PCP).

The school is responsible for starting the planning process and does this while continuing to deliver the kind of curriculum which maximises independence and confidence.

The views of a range of professionals from education (including staff who work closely with the young person), social care, health and voluntary sector, are sought at a meeting. This meeting kick starts a series of actions that end up with a coherent plan which the young person and family is happy with.

When the process works well, young people can achieve a way of living which they have chosen, or helped to choose, which gives them opportunities to continue to develop their independence, aspirations and life style.

Getting a result is a planning tool for families that can help. Find out more information here: [www.sense.org.uk/publications/getting-result](http://www.sense.org.uk/publications/getting-result)

## Young people's views

The young person is at the centre of the planning process – and facilitating their “voice” and hearing their thoughts is at the centre of the process. This will not be a problem for young people who have good communication skills, but facilitating their input will still require planning.

The views of young people with profound impairments and very limited communication must be facilitated, even though this may seem challenging.

Parent carers thoughts are essential as well. Their views are crucial as their child's future effects their own.

## Helping young people with MSI choose what they want out of life

Even with the best communication support, participation in a discussion about the future is difficult for many people with MSI. Why?

Because:

- They find it hard to think and communicate about events beyond their experience.

Most young people with MSI need to try things out to learn about them: repeated visits or a trial period to “taste” a college course, new home, club or other setting will be required before an opinion can be sought.

- They lack the full information needed to make meaningful choices in a meeting environment.

Most young people communicate much better with people they know and trust. Familiar staff or family members can use the right combination of speech, sign, symbols, gestures and read body language more effectively

- Some young people have changing needs, because their health, vision or hearing continue to change

For example adolescents with Usher syndrome may be experiencing changes in their night vision - just as their lives are opening up socially. Career plans may be affected and the planning process should focus on listening to the young person and finding solutions.

## Leaving school – what next?

### Continuing education

Continuing in education is a very good option. The principle of “life-long learning” works well for young people who have Multi-sensory impairment (MSI). The type of course and college will depend very much of the individual’s aspirations and abilities. Finding the most suitable place to study may take a little research.

Some young people will take the same path as hearing /sighted peers – choosing courses leading to academic or vocational courses at University or other forms of higher education. These institutions have a designated coordinator who can offer support.

Others will want to find specialist courses for students with sensory impairments that can build on the skills and knowledge they have developed at school: focusing on personal development and becoming independent.

There is a range of providers including local colleges and **national specialist colleges** (**NATSPEC** - [www.natspec.org.uk](http://www.natspec.org.uk)). Some of the specialist colleges are residential and provide a first taste of independence from home. Information about *all* the options should be readily available to your family and welcome visits from your son or daughter. Voluntary organisations, like **Sense** can help with information, advice and support when considering the options.

### Thinking about where to live

MSI creates a wide range of needs, so that some young people will live completely independently whilst others need full support. For every young person and their family the question must be asked: what kind of support or training do I need to make a more independent lifestyle work?

## A move away from the family home

With the right support all young people with MSI can leave home and make a life for themselves. Developing new skills and interests and meeting new people is all part of growing up. However this requires careful thought and planning.

Moving away from home may mean being:

- Supported in their own home.
- Supported with other young people in a jointly tenanted house.
- Joining a larger house with a number of a people of a similar age and communication needs.

The level of human and technical support required would depend on individual need.

## Staying at home and living with the family

Choosing to live with the family into adulthood also requires proper planning. There should never be an expectation from social services that staying at home is an automatic move after school or college. It's a choice that needs proper consideration, as it involves the lives of the whole family.

In considering this as an option, the kind of support required to make it successful should be identified before any decision has been taken. As living at home as an adult is not the same as when a child, this change needs to be respected when planning support.

This could include:

- **Intervenor** or guide/ communicator or social care worker.
- Day service place for continuing education and social engagement.
- Adaptation to the home.
- Appropriate equipment and aids.
- Regular planned short breaks for family.
- Ongoing help and advice from specialists such as **occupational therapists** and **habilitation workers**.

You may have concerns about what may happen as you get older or if illness prevents you from being so active. Independent living is always an option.

## Going to work

For those young people with Multi-sensory impairment (MSI) who have gone on to study at University or college you may find that by the time they are in their early twenties they will be in training for employment, or will already be in work.

An Access to Work grant is money to help someone find work or stay in a job. It's for people with **additional needs**, health or mental health conditions. Find out more information here: [www.gov.uk/access-to-work/overview](http://www.gov.uk/access-to-work/overview)

The money can pay for things like:

- Specialist equipment.
- Travel when you can't use public transport.
- A communicator at a job interview.

How much money you receive depends on your circumstances.

Young people who have a condition that may cause them to lose hearing or vision in adulthood may have a job role that will eventually prove difficult to carry out. Because the rate of change is hard to predict it will certainly be source of anxiety.

Finding suitable employment is one the hardest challenges that face young people with MSI. Many tackle work experience while at school or college and try out various job roles.

All this helps in deciding what kind of a job a person could do successfully. However, finding paid employment is much more difficult.

Help is available from a Disability Employment Adviser (DEA) at your local Job centre.

## Developing independence

Independence is a critical life skill for all children, young people and young adults. While for children without additional needs independence is often seen as the child being able to do something without help, for many young people and young adults with MSI, this may not be achievable in certain areas of their lives. So for these families, independence is seen in terms of a young person or young adult reaching their potential in carrying out life skills, *with* or *without* support.

The kind of things *all* young people and young adults want to do independently include being able to make snacks and meals, go out alone, handle money and manage unforeseen circumstances when out and about. They want to make friends, choose for themselves, and decide what to wear and how to spend time.

Young people with MSI will not learn these skills incidentally but will require direct teaching as preparation for adulthood. So, effective strategies are required from early on in a school career to foster future independence.

Learning what life outside schools will be like, how decisions are made and when to ask for help will all need to be discussed and experienced. Role play can help in this.

Organising study, work or leisure and managing time should also be part of the curriculum.

Alongside these a number of very basic skills associated with running a home including shopping, budgeting, cooking, cleaning will need practice.

## Letting go

Parent carers are often so anxious to get their child's needs met they forget to take their own into account.

Creating a life once children have grown and left home can be quite a challenge. If you have been a "24 hour carer" as well as a parent carer you may worry that the people caring for your child may not be attentive enough. Satisfy yourself about the quality of the service being provided and give yourself time to adjust. It will take time.

You will still be most welcome at the groups you have been a part of and your knowledge and understanding will be valued and sought by others families.

However, as family life has been so all consuming careers have been curtailed, travel plans have been put on hold and hobbies have been neglected. The opportunity may be there now.

## Top tips

- Be kind to yourself. Caring is not easy and you need to give yourself time to rest and recoup your energies and to stay in touch with family and friends.
- Your child needs you to be their parent/carer first and not their teacher or therapist. This means take the time to be close to your child and to enjoy getting to know him or her.
- When you are playing with your child find out how your child communicates that they like or don't like something and tell other people so they can understand your child's body language.
- Your child may need extra time to process the information that they receive from the world around them and to respond accordingly.
- Have daily routines such as a consistent bed time routine. This will help your child feel secure and encourage their understanding of what is going to happen next.
- Include your child in the whole process of an activity such as going to the fridge together to get a yoghurt, so that things don't seem to magically appear out of nowhere.
- Make it easier for your child to move around the home independently by avoiding clutter and not rearranging the furniture suddenly.
- Make the most of your child's residual hearing and vision by ensuring that your home has the right lighting levels for them and by encouraging them to wear their hearing aids or glasses.
- You and your child will benefit from having the support of professionals and other parents who know about MSI such as a specialist qualified teacher of MSI, a social worker or mobility specialist.
- Ask questions to find out how the system works when you need a break or help to decide on the right school, the right support at school or what happens after school.

## Resources

### Books

#### **Remarkable Conversations: A guide to developing meaningful communication with children and young adults who are deafblind**

*Miles & Riggio (editors), 1999, Perkins School for the Blind*

#### **Communication and congenital deafblindness booklets:**

Book I: Congenital deafblindness and the core principles of intervention, *Rodbroe & Janssen, 2006, VCDBF/Viataal*

Book II: Contact and social interaction, *Janssen & Rodbroe, 2007, VCDBF/Viataal*

Book III: Meaning making, *Souriau, Rodbroe & Janssen (editors), 2008, VCDBF/Viataal*

Book IV: Transition to the cultural language, *Souriau, Rodbroe & Janssen (editors), 2009, VCDBF/Viataal*

#### **Teaching children who are deafblind**

*Aitken, Buultjens, Clark, Eyre & Pease, 2000*

#### **Deafblind infants and children: a developmental guide (2nd ed) McInnes & Treffry, 2001**

#### **Child-guided Strategies: The Van Dijk Approach to Assessment Van Dijk, Nelson, Oster & McDonnell, American Printing House, 2010**

#### **CHARGE syndrome**

*Hartshorne, Hefner, Davenport & Thelin, Plural Publishing, 2010*

#### **Deafblindness and cochlear implantation**

*The Ear Foundation/Sense, 2010*

#### **Deafblindness and cochlear implantation: a practical guide**

*The Ear Foundation/Sense, 2012*

### Downloads

#### A Curriculum for Multi-Sensory Impaired Children

*Murdoch, 2010, Sense/Victoria School MSI Unit*

[www.sense.org.uk/content/msi-curriculum](http://www.sense.org.uk/content/msi-curriculum)

#### Quality Standards in education support services for children and young people who are deafblind/ multi-sensory-impaired

*Sense, 2002*

[www.sense.org.uk/publications/quality-standards-education-support-services-children-and-young-people-who-are](http://www.sense.org.uk/publications/quality-standards-education-support-services-children-and-young-people-who-are)

Getting a result Information and ideas to help young people who are multi-sensory impaired and their families understand and participate more fully in the transition planning

process. Book and DVD

*Boothroyd & Murdoch, Sense, 2010*

[www.sense.org.uk/publications/getting-result](http://www.sense.org.uk/publications/getting-result)

Intervenors in Action DVD

[www.youtube.com/watch?v=oC1bJBwydhk](http://www.youtube.com/watch?v=oC1bJBwydhk)

*Sense, 2012*

[www.sense.org.uk/content/intervenors-action-dvd-order-form](http://www.sense.org.uk/content/intervenors-action-dvd-order-form)



## Useful organisations and websites

### Sense

The national charity that supports children and adults who are MSI and deafblind. They provide tailored support, advice and information as well as specialist services to all deafblind and MSI people, their families, carers and the practitioners who work with them.

Web: [www.sense.org.uk](http://www.sense.org.uk)

Tel: 0845 127 0066

### Action on Hearing Loss (formerly the 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 providing services, campaigning, lobbying, raising awareness of deafness, and through social, medical and technical research.

Web: [www.actiononhearingloss.org.uk](http://www.actiononhearingloss.org.uk)

Helpline: 0808 808 0123

### Advisory Centre for Education (ACE)

An independent advice centre offering information about state education in England and Wales. Although most of their information relates to children over five, it can advise on special education for younger children.

Web: [www.ace-ed.org.uk](http://www.ace-ed.org.uk)

Advice line: 0808 800 579

### Alström Syndrome UK

Supports people with Alström Syndrome, their carers and the practitioners who are working with them.

Web: [www.alstrom.org.uk](http://www.alstrom.org.uk)

### Carers UK

Run by carers to provide support to anyone who is a carer. They offer information and advice, produce a range of publications and also campaign for carers' rights.

Web: [www.carersuk.org](http://www.carersuk.org)

Carers Advice line: 0808 808 7777

### CHARGE Family Support Group

The group's aim is to create a positive, supportive network of individuals, parents, families and practitioners to share ideas, experiences, information and give vital support to people with CHARGE syndrome and their families

Web: [www.chargesyndrome.org.uk](http://www.chargesyndrome.org.uk)

Tel: 020 8265 3604

### Citizens Advice Bureau

Help people resolve their legal, money and other problems by providing free, independent and confidential advice, and by influencing policymakers. There are branches in most towns and cities.

Web: [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

Tel: England - 08444 111 444 Wales - 08444 77 20 20

### Contact a Family

Helps families who care for disabled children and those with other additional needs or special need. They are a main source of information about rare disorders and are able to put families in touch with one another.

Web: [www.cafamily.org.uk](http://www.cafamily.org.uk)

Helpline: 0808 808 3555

### Equality and Human Rights Commission

The Equality and Human Rights Commission has a statutory remit to promote and monitor human rights; and to protect, enforce and promote equality across the nine "protected" grounds - age, disability, gender, race, religion and belief, pregnancy and maternity, marriage and civil partnership, sexual orientation and gender reassignment.

Web: [www.equalityhumanrights.com](http://www.equalityhumanrights.com)

Phone: 0800 444 205

Textphone: 0800 444 206

### Early Years Equality

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

Web: [www.eearlyyearequality.org.uk](http://www.eearlyyearequality.org.uk)

Tel: 0114 2700214

Email: [enquiries@earlyyearequality.org.uk](mailto:enquiries@earlyyearequality.org.uk)

### Guide Dogs

Train and provide guide dogs for visually impaired people and also those with a dual-sensory loss.

Web: [www.guidedogs.org.uk](http://www.guidedogs.org.uk)

Tel: 0118 983 5555

### Include Me Too

Include Me Too supports disabled children, young people and their families from Black, ethnic minority and other marginalised backgrounds and aims to promote and support all disabled children and young people's rights.

Web: [www.includemetoo.org.uk](http://www.includemetoo.org.uk)

Tel: 019023999888

### Makaton

A form of sign language often used with people who have learning disabilities.

Web: [www.makaton.org](http://www.makaton.org)

Tel: 01276 606 760

### Mencap

Provides support so that people with a learning disability can live as independently as they want.

Web: [www.mencap.org.uk](http://www.mencap.org.uk)

Learning Disability Freephone Helpline: 0808 808 1111

### National Consortium on Deaf-blindness

American library articles relating to deafblindness.

[www.nationaldb.org/ISLibrary.php](http://www.nationaldb.org/ISLibrary.php)

### 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 provide opportunities for young deaf people to develop social skills, confidence and independence. They also campaign on behalf of deaf children and their families, and work with practitioners and policy makers to ensure high quality services are available for all.

Web: [www.ndcs.org.uk](http://www.ndcs.org.uk)

Helpline: 0808 800 8880

### NATSPEC

An association for independent specialist colleges that provide further education for students with learning difficulties and/or disabilities

Web: [www.natspec.org.uk](http://www.natspec.org.uk)

Tel: 0117 923 2830

### Princess Royal Trust for Carers

The largest provider of comprehensive carers support services in the UK, including services for young carers.

Web: [www.carers.org](http://www.carers.org)

Tel: 0844 800 4361

### Royal National Institute of Blind people (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.

Web: [www.rnib.org.uk](http://www.rnib.org.uk)

Helpline: 0303 123 9999

### Scope

Provides services for people with cerebral palsy. They develop and promote a number of local and national initiatives to enable them to achieve equality.

Web: [www.scope.org.uk](http://www.scope.org.uk)

Helpline: 0808 800 3333

### Skill – the Bureau for Students with Disabilities

Skill is now run by Disability Alliance. It will provide updated information, policy development, a young person's website and a freephone helpline.

Web: [www.skill.org.uk](http://www.skill.org.uk)

Helpline: 0800 328 5050

### Transition Information Network

A network for parents, carers, disabled young people and people who work with and for disabled young people in transition to adulthood.

[www.transitioninfonet.org.uk/home1.aspx](http://www.transitioninfonet.org.uk/home1.aspx)

## Glossary

**Academy school** - Academies are publicly-funded independent schools that are not in the control of the local authority

**Additional needs** - The term 'additional needs' used in this and other Early Support resources is used to refer to any child or young person who has a condition, difficulty, challenge or special educational need, whether diagnosed or not, who is likely to need additional support beyond universal services.

**Alström syndrome** - Alström Syndrome is a genetically inherited disease, which affects a wide range of important body functions. The disease causes progressive blindness and hearing loss in most people, who may also have a number of other major-organ related conditions.

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

**Congenital loss, acquired loss or degenerative condition** – A loss present at birth, a loss that can occur at any time in one's life, as a result of an illness or injury, a condition that changes and worsens over time.

**CHARGE syndrome** - CHARGE is a challenging genetic condition that can affect all ages from birth. The most common problems are with the ears, eyes, heart and nose – although there are a wide range of other difficulties that people can have.

**Deafblind Guidance** - Relevant to all local social services staff and requires specific actions to be taken such as identifying and keeping records on deafblind people in catchment areas.

**Free schools** – All-ability state-funded schools set up in response to what local people say they want and need in order to improve education for children in their community.

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

**Intervenor** - 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**.

**Person centered planning** - A set of approaches designed to assist someone to plan their life and supports.

**Resonance boards** - A resonance board is a small raised platform made of plywood attached to a wooden frame. This is a great environment for encouraging a child to attend to and explore sounds through play. Any movement on the surface will produce amplified sound and matching vibration that will be felt through the whole body.

**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.

**Statutory process** - Enacted, regulated, or authorized by statute.

**Tactile defensiveness** - Refusal to touch things. Hands are often withdrawn.

**Tactile sensitivity** - Distress or discomfort resulting from touching certain textures.

**Total communication** - Is an approach to education that aims to make use of a number of modes of communication such as signed, oral, auditory, cues and objects.

**Transitional Planning** - A Transition Plan helps you to plan what you want to achieve in your teenage years, and for your future, as you move into adult life.

**Usher Syndrome** - Usher syndrome is a genetic condition that develops sight and hearing loss growing up and getting older. There are three types of Usher syndrome, sight loss is caused by an eye condition known as retinitis pigmentosa and hearing loss is usually sensori-neural deafness experienced from birth.

**Voluntary organisations** - Community and not-for-personal profit **organisations**.

## Glossary of practitioners

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

**Care staff** - 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** - 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 practitioners about hearing assessments, hearing aids and hearing support.

**Educational psychologist** - An educational psychologist has a degree in psychology and additional specialist training. They 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.

**Equality Named Coordinator (ENCO)** - A staff member who supports a setting to plan and meet the equalities need of each child and supports the setting- early years, play care. School - to develop and implement policies and procedures that give due regard to equalities and good relations between different groups. The ENCO and the SENCO complement each other's work with disabled children, taking both an impairment/SEN approach and a holistic equalities approach.

**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.

**Habilitation worker** - Works with visually impaired children and young people to develop skills towards mobility and independence whether in the home, education or social environments. They work in collaboration with qualified teachers of children with visual impairments.

**Health visitor** - 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** - A specialist learning support assistant who works one-to-one with a child or adult with MSI. They provide information that would normally come through sight or hearing and help the child to understand, to communicate and to access the environment.

**Key worker** - See **care coordinator** for further details.

**Learning support assistant** - A learning support 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.

**Link worker** - See **care coordinator** for further details.

**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 doctor who specialises in the brain and nervous system.

**Occupational therapist** - An occupational therapist is concerned with difficulties that children have in carrying out the activities of everyday life. They help children improve their functioning by therapeutic techniques and advise on adaptations in the home and the use of specialist equipment.

**Ophthalmologist** - A doctor based in a hospital who specialises in the diagnosis and treatment of eye defects and diseases. They treat eye disorders 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** - A health professional who specialises in 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 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 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** - A Portage home visitor provides home-based educational support service for pre-school children with additional needs. Their service is usually provided through a local authority.

**Portage worker** – See **Portage home visitor** for further details.

**Social worker** - A professional who supports children and families by advising on appropriate services and introducing families to some of the services they need, such as counselling, transport, home helps and other services. They may also be able to help you to claim welfare benefits and obtain 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 QTMSI QTVI QTHI** - 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: **qualified teachers of children with MSI (QTMSI)**, **qualified teachers of children with visual impairments (QTVI)** and **teachers of children with hearing impairments (QTHI)** (also called teachers of the deaf). **Qualified teachers of children with MSI** provide support to children with MSI, their families, and to other practitioners who are involved with the child's education. **Qualified 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 parent carers 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.

**Teaching assistant** – See **Learning support assistant** for further details.

# Early Support

for children, young people and families

[www.ncb.org.uk/earlysupport](http://www.ncb.org.uk/earlysupport)

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**sense**  
for deafblind people

**Early Years Equality**  
*removing racism • defying discrimination*

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