Early Support

Helping every child succeed

Getting Stuck?

More ideas for you and your child

About this booklet

Helping your child to learn can be a daunting task for parents – particularly when your child has limited vision.

Parents often feel unsure about how to help their child move forward. Some skills seem to take a long time to learn, while other behaviours persist and don't appear to change at all. Some things that young children do are unexpected – they fall outside typical patterns of development – and this is confusing and sometimes challenging for families.

These are the 'sticky areas' discussed in this booklet. Some are issues for all young children and some are more likely to be found in young children with limited vision.

This booklet:

- explains about these 'sticky areas'
- gives some practical ideas for moving forward
- makes suggestions for where to look for extra help if you need it.

It aims to give parents more confidence in handling areas that seem to be difficult and a clearer idea about when additional help might be needed.

It is published as part of the Early Support *Developmental journal for babies and children with visual impairment*. Whenever the text talks about 'stages', it means the stages of development defined by the Developmental journal.

Where words are printed in blue, like this, they appear in the Glossary.

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Introduction

All parents can find children's behaviour difficult, puzzling or challenging. Many worry at some point about their young child's development. They wonder whether it's 'normal' and what particular behaviours mean. They ask 'Is my child learning things at the right age?' 'Why do they do this so much (or so little)?' and most importantly, 'What can I do to help them move on?'

It's reassuring to realise that some behaviours are part of normal development in young children and that they may have an important function to play at a particular stage. These sorts of behaviour change naturally as children become more mature. The Developmental journal can help you decide whether the skill level or behaviour you're concerned about is appropriate to your child's general stage of development. If it's what you would expect to see, given your child's other skills, it's probably developing appropriately, in line with their general rate of learning.

However some behaviours and skills can seem to be out of step with other aspects of a child's development – your child may seem to be rather behind in particular areas or what they do doesn't seem to 'fit' with anything described in the Developmental journal.

Your child has become 'stuck' if their behaviour doesn't seem to be developing and maturing as you would expect, or has become very persistent at a particular level. Some behaviours are more prone to 'getting stuck' in young children with limited vision, though the reasons for this are not fully understood. A few behaviours, such as eye poking, are distinctive to young children with certain visual disorders and limited vision.

Making a start

Take time to reflect on what your child is currently doing.

You may find it useful to talk about your concerns with your professional advisor and to plan ways of helping your child together with them.

First of all, think about the behaviour or skill area that's worrying you and consider the following questions:

- Is it appropriate for my child's level of development? If so, it will probably develop and change as other skills and areas of development move forward.
- How frequently does my child do it?
- Does it get in the way of other behaviours that are developing or in the way of other learning?
- Is it very persistent and does it cause distress for my child, or to other people?
- Am I or my child able to control or shape the behaviour and turn it into something more appropriate?
- How long has this behaviour been going on?

The ideas in this booklet may be helpful if the answer to the question How long has it been going on? is:

- more than six months, if your child is under 15 months
- more than 8–12 months or roughly the period of one stage in the Developmental journal, if your child is older than 12–15 months.

It's most helpful to ask these questions when you have already used the Developmental journal and tried some or all of the ideas on the relevant Activity cards.

Your answers to these questions may indicate that the behaviour you're thinking about doesn't seem to have changed for quite a long time. It may have become persistent and difficult for your child or your family and be interfering with play, and other learning and everyday experiences.

If you're convinced your child is 'stuck', then it's time to consider some further ideas for helping them to move on.

Talk to your professional advisor about your concerns and look together at relevant sections of this booklet. They should be able to advise you if any further help is required.

The sections called Moving on provide practical ideas for things you can do to help.

The sections called Signposts to extra help tell you who to contact to get further specialist advice.

Touch or tactile sensitivity

Babies and young children learn a great deal about touch in the first years of life as their hands start to explore the world. Limited vision reduces the motivation to explore and a baby's hands may stay passive in the early months. This can limit access to a wider range of sensory experiences. Babies may not be able to predict or work out what they're about to touch and this may make them more wary of touching new things. They may find it difficult to recognise or interpret what's being touched. Objects put suddenly into the child's hands can be especially unpleasant, since the child does not have time to prepare for the tactile experience.

Young children with limited vision rely on their hands (and feet) to interpret the world more than children who see what they're about to touch. This may make their hands, finger tips and feet particularly sensitive and aware of tactile sensory experiences. Hyper-awareness or sensitivity is called tactile sensitivity. Different textures and materials may become experienced as positive and pleasant or negative and aversive.

If the tactile experience is unexpected, confusing or overwhelming, young children may start becoming reluctant to touch or hold objects and materials. This is called tactile avoidance. It's not uncommon that a young child with limited vision develops a persistent refusal to touch certain textures or substances.

Smooth firm textures with a uniform surface and neutral temperature are often the most readily accepted – for example, wood, metal, plastic, cotton. Other substances, such as fluffy, soft materials (like a fluffy ball) or sticky, wet, gooey substances (like wet cereal, banana, sticky playdough, finger paints or glue) are experienced as more unpleasant. Prickly materials like the bristles of a brush may also be initially disliked. Grainy and shifting materials, like sand or grass, may be experienced as unpleasant – whether underfoot or in the hands. Some children get very upset or agitated if made to touch any substances that they dislike.

If your child is showing persistent dislike and avoidance of touching certain things, then some of the following ideas may help.

Check first

- Look at the ideas under Play and learning and Using hands: Learning with touch and Response to different textures on the Activity cards.
- Go back to the ideas of the previous stage if your child seems to have got stuck at a particular stage. They may just need more opportunity and experience at the previous level.
- Give plenty of opportunity for feeling and exploring textures and materials at every stage of development.

Moving on

- Always use a forewarning approach if you're handing your child any object or textural substance. This may be through touch alone – taking it over the back of the fingers and finger tips and letting your child take time to open their fingers, rotate their wrist and take the object into their palm. Forewarning can also be done by making a sound with the object, talking about it, letting the child smell or (if sufficient vision) see it first.

- If your child is showing dislike of a particular texture, present it first on less sensitive parts of the body such as the tummy or leg (rather than the hand, which is most sensitive). Gradually work towards the hand or foot by moving the texture slowly along the arm from the elbow to the wrist or from the knee along the lower part of the leg. Do it with a medium, even (but not hard) pressure because if it's too light this can be even more stimulating. Once it is tolerated on the arm or leg, use a forewarning approach to take it over the back of the hand.
- It's important not to put your child's hands (or feet) directly into or on substances that they find unpleasant and aversive. Don't put objects directly into their hands either. Children feel most secure when they have control over incoming sensations, so let them choose whether to feel or hold it.
- You can use a shared discovery approach (touching their forearm or elbow) to show your child that you're interested and involved when they explore a particular texture.
- Gradually introduce new textures and toys that are similar to but slightly different from the ones that your child is comfortable with and that are closer to those that are a problem. This can be done in gradual steps, with the texture or toys becoming increasingly similar to the 'unwelcome' ones, eg attach a new material that is a little different and closer to the sensation that they find uncomfortable in a crinkly book that your child already likes playing with. For example, if fur is a problem, add a small piece of suede.
- If wet messy play is a problem, try playing with food – begin with dry cereal in a bowl and give your child time to touch, taste, smell and play with this alone. When this is tolerated, gradually introduce something a bit 'gooier' or softer, especially if it's a food they enjoy, like mashed potato.

- When your child is starting to learn about words, use words to describe the textures and objects that they're about to feel, eg 'rough', 'fluffy', 'soft', 'smooth', 'cold', 'hot'. For example, you might say 'Here comes a very prickly hedgehog'. This helps children to predict and understand what they're about to feel and may lessen their anxiety.

In the end, it doesn't matter if your child never gets to like 'playdough' or certain substances, but what does matter is how they use tactile exploration in new situations. The aim is to get them exploring and touching new materials and objects confidently.

Signposts to extra help

If your child continues to experience excessive sensitivity or avoidance of certain textures and this interferes with everyday routines and their exploration and learning, further advice can be sought from your specialist teacher for visually impaired children or from an occupational therapist.

Sound or auditory sensitivity

Young children with limited vision are very aware of sounds in general and some may develop a particular awareness of certain sounds. This is called auditory sensitivity. They may show a preference for some sounds and a strong dislike of others.

As with touch, unfamiliar or sudden or disturbing sounds, like a hoover or a hairdryer, may cause anxiety and agitation. Public areas with loud, unpredictable and echoing sounds, like swimming pools, supermarkets or stations, may also cause distress. In some cases, children may develop an aversion and avoidance of a particular sound – for example, hand clapping, the doorbell or the lawn-mower. A particular toy, eg a noisy music box or an 'exciting' and noisy electronic game, may overwhelm the child. As with touch, it's helpful to think about how sounds in the environment can appear disconnected and disturbing if you can't see and understand the source of a sound and so you don't know where it's coming from.

Some sounds, especially those that are tuneful, melodic and familiar, may be experienced as especially pleasant and positive – for example, music, songs, familiar themes on TV or tapes, and language. A young child may seek out pleasant sound experiences and strongly avoid those that they dislike.

Young children with limited vision rely on sound to make sense of the environment and may therefore find the auditory or sound environment much more tiring and perplexing than a sighted child who can screen out (not listen to) unwanted auditory distractions.

If your child is showing persistent rejection or fear of particular sounds, then the following ideas may be of help.

Check first

- Look at the ideas under Play and learning and Using hands: Learning about sound and Communication, language and meaning: Listening on the Activity cards. These will lead to better understanding of sound experiences and help your child feel secure in the world of sound.
- Go back to the ideas of the previous stage if your child seems to have got stuck at a particular stage. They may just need some more opportunity and experience at that previous level.
- Start with quieter sounds and then gradually introduce more noisy or disturbing sounds as your child becomes more confident about the sounds in their environment.

Moving on

- Always prepare your child for noises that may frighten or be overwhelming. Say 'I'm just going to put on the noisy hoover. Vroom vroom!' before you switch it on. Also prepare your child for where the noisy object is going to go – and reassure them about their own safety – 'I'm going to hoover the sitting room but I'm not coming into the dining room'. If possible, introduce a scary noise from a distance – such as the next room or the other end of the garden.
- Your child may be scared to approach an object that makes the noise they don't like, but you can then help them to approach and feel it, once the noise has been turned off.

- As your child's language understanding increases, you can explain what the object does (and show them) – 'That noisy hoover is making the carpet nice and clean', 'The lawnmower's cutting the grass'.
- Sudden loud noises in the street, eg an ambulance siren, need calm reassurance and explaining.
- Your child may be frightened of loud, noisy and echoing public places, such as the supermarket, the swimming pool, their nursery school or parties. Introduce them in stages to these environments – for example, only taking them to quieter shops at first, or to the pool when it's quiet, or to a tea-party if there are only a few children. Once confident in these environments, you can gradually introduce your child to louder settings. Children with limited vision need explanations of where they are, what's going on, and what all the sounds they can hear are.
- If your child initially rejects a particular sound and shows agitation, introduce it again for shorter periods at a quieter volume or a greater distance, or use a similar or less intrusive sound. Also explain what the sound is and prepare your child before introducing it or mimic the sound before making it. Offer opportunity and encouragement to listen to the sound and praise them for listening to it calmly. Don't introduce the sound for too long. Children gain trust and confidence as experiences become more predictable. Then you can gradually increase the volume or reduce the distance from the child as they become more tolerant and confident about the sound.

Signposts to extra help

If your child continues to experience excessive sensitivity or avoidance of certain sounds and this interferes with everyday routines and exploration and learning, it would be advisable to seek further advice from a speech and language therapist who can advise on auditory skills or a developmental paediatrician or psychologist who can give advice on how to desensitise your child to the sound.

Practical everyday activities

Difficulties with movement and mobility

There is great variation in the rate of motor development in all children. Some walk independently at nine months, others don't do this until 18 months. In general, movement skills develop more slowly in children with limited vision and especially those with the most limited vision.

Babies and children with limited vision can get stuck at different stages. Movement and mobility require not only the development of co-ordination and control of body movements but also an understanding of what movement can achieve. This understanding is needed to motivate moving when vision is very limited.

Learning to sit requires the development of postural control (development of muscles of the trunk to develop a straight back), balance and saving reactions (learning to put their hands out to the floor or to the side to balance when they tip over). This includes understanding and anticipating the floor as a solid base.

Learning to move around requires more complex co-ordination of movement and the motivation to move, provided, for example, by wanting to reach a sound-making toy. Sound localisation skills, ie knowing where a sound is coming from, are important for this. Children with limited vision are more likely to move along on their bottom (bottom shuffle) rather than crawl. This may be because they can keep their head up and use any vision they have to navigate. Bottom shuffling also keeps hands free for reaching out, navigating and exploring.

Learning to stand requires the development of postural control, strength in their legs, balance and the motivation and confidence to reach to pull yourself up. Once standing, independent walking requires the use of these skills to walk upright and the motivation and confidence to walk without support and navigation and spatial understandings to avoid obstacles and take routes.

Check first

- The developmental processes in learning to sit, to move, to stand and gain skilled mobility are covered in the Movement and mobility sections of the Developmental journal.
- Ideas and suggestions about how to help to develop these skills are given in the Activity cards at the appropriate stages.
- It's a good idea to work across all the developmental areas of the Developmental journal at each stage. Achieving goals in other areas of development, like learning about sound and sound localisation or developing an attachment to the parent, helps develop the motivation to move.
- Your child will not be ready to move on to another level until they've reached the appropriate maturity for developing the next step.

Moving on

- If your child is still not moving on, try going back to the previous stage and ensure your child has established earlier skills.
- Encourage plenty of opportunities for movement and mobility appropriate for the child's current level of development.
- Then return to the present stage and try breaking the developmental goals down into smaller steps.

Signposts to extra help

If your child continues to experience difficulty moving on to the next stage of mobility it would be advisable to seek further advice from a paediatrician who may refer you to a physiotherapist or to an occupational therapist.

Eating and feeding difficulties

Many families experience feeding difficulties with children under three years of age. There are a variety of reasons why these occur in children. All babies are different – some eat what they're given without protesting, while others are fussy or not interested. Eating and feeding is also a developmental process with new skills and abilities that have to be learned at each stage. Parents are naturally and always very concerned if their child is having difficulty eating, feeding or drinking.

It's useful to know that eating habits and appetite need not be affected by limited vision. Many children with limited vision learn eating and feeding skills with no difficulty. However some children do experience difficulties at different stages.

Your baby's reactions to feeding depends on a range of factors including their temperament, their taste preferences and how well they use their other senses. Your attitude and reactions may play a role as well, as might your home circumstances around meal times. It will help if you can try to be relaxed around feeding time, as babies and young children can pick up your anxiety.

Sometimes, however, difficulties during feeding are linked to physical and medical difficulties, including delayed motor development or other medical problems. It's a good idea to have these checked out first to ensure that there are no medical reasons for a feeding difficulty.

Some children have more difficulty accepting lumpy food when it's first introduced or later (around Stages 2–3) when they may start to reject many foods which they enjoyed when they were younger. They express their preferences more clearly and start exerting more control over their environment by choosing what they want to eat. This tends to occur at the stage when children are becoming more independent and self-directed. This can be a very challenging time for parents who are trying to maintain a sufficiently healthy and varied diet.

Read more about this in the section on **Resistance to adult direction** on page 21

If you and your child get 'stuck' with feeding behaviour, then the following ideas may be helpful.

Check first

- Turn to the Towards independent self-care: Feeding and eating sections of the Developmental journal for information about typical patterns of development for feeding and eating skills.
- Your child will not be ready to move on to another level until they've reached the appropriate maturity for developing the next step. The accompanying Activity cards give suggestions on practical ways to help at each step of development.
- If your child is having difficulty moving on, then you may find it helps to go back to the earlier cards and ensure their skills are well established at this stage.

Moving on

Accepting new foods – tastes and textures

- If you're having difficulties introducing blended or pureed foods and weaning off milk, then think about whether your baby is ready. This will usually be during Stage 1b (in the Developmental journal). The Activity cards for Stage 1b give ideas and suggestions about introducing pureed foods and weaning.
- The introduction of new tastes and textures takes time, so persevere. However, we all dislike some foods, so if your baby constantly rejects one food while accepting others, then respect their wishes and maybe try it again in a few weeks or months' time.
- If your child is still rejecting food at Stage 2 or 3 or even later, it's important to keep gentle control but not to turn meal time into a battleground.

A good idea is to continue with a set routine of dishes (eg a savoury or vegetable course followed by a fruit or sweet course) every day so that your child knows what the expected order of flavours and foods is going to be. If they don't eat everything, take away uneaten food without coaxing or making a fuss and reintroduce it patiently in a few days' time. The aim is to keep the food routine going and to give your child the opportunity to try rejected foods again, later on, but without making a battle of this.

- It's not advisable to keep switching and changing foods to follow the child's whims, since this can put young children in charge of their feeding regime and they may become very restricted in what they choose.
- If eating habits are not as healthy as you wish, be patient and persevere. Try mixing nutritious food with favourite foods.
- At this stage having a family meal time is especially important, so that your child can hear and see others eating in a relaxed atmosphere. Let your child have some of their favourite foods and some foods that they're less fond of.
- Don't 'degrade' certain foods by saying 'You can have some lovely ...(liked food) if you eat your... (disliked food) first'. Children quickly pick up on this attitude about some foods being less desirable.
- Later, as the child develops more language and awareness of what other people are doing, you can talk about how they are enjoying the food your child doesn't like so much. It's advisable however not to give any attention to or talk about the child's dislike of certain foods since this tends to reinforce these feeding habits. Without pressure you may find they will eventually give rejected foods a try.
- Give your child smaller portions of foods that they have a preference for so that they don't fill up with the things they most like eating and therefore have no appetite for other foods.

Some children become very fixed on a limited range of foods, despite parents following all the advice given above. They may also show other difficult and restricted behaviours and be making limited developmental progress.

Find out more about this in the section on **Resistance to change** on page 24

Finger feeding and tactile sensitivity

- Some children with limited vision are reluctant to touch unfamiliar things and are very uncomfortable with wet or cold textures. This can delay finger feeding and the development of hand skills in general.

Find out more about this in the **Touch or tactile sensitivity** section on page 4

Using a spoon or fork independently

- Understanding about a spoon or fork as a 'tool for eating', the 'loading' of a spoon, and learning to stop food falling off a spoon (gravity) are all difficult concepts for a young child with limited vision. Even babies with full sight naturally turn a spoon over as it approaches their mouth.
- The stages of development of these skills are given in the Eating and feeding sections of Towards independent self-care in the Developmental journal. See the Activity cards that are linked to these sections, too. Young children with limited vision will need patient teaching of these skills at the appropriate time in development.
- It's likely to be very messy and frustrating for the child in the early days, but it is important for your child to practise. This will support growth in skills in using a spoon (and later a fork). Give enough support to prevent your child getting too frustrated, but reduce this steadily as they get more successful.

Signposts to extra help

If your child continues to show specific difficulties in feeding and eating you need to consult your specialist health visitor, GP or paediatrician, who can advise on further assistance.

Sleeping difficulties

Bedtime can be a very challenging time of the day for parents. It's estimated that about one in five children have difficulty settling to sleep or don't sleep through the night until they are over three years of age. If you and your child are sleep deprived you can't function properly and quality of life can be seriously affected. Tired babies are often unhappy and do not learn as well as contented, rested children.

In all children the development of a settled sleep pattern is a developmental process with biological and social aspects to the development. Babies have an internal biological clock which helps establish regular patterns of waking and sleeping. At first these patterns are very much dictated by the baby's own internal waking, sleeping and

feeding needs. In the first few months of life, babies tend to have frequent periods of waking and sleeping, which are relatively brief, often lasting 1–3 hours of sleep or waking at a time. Frequent waking coincides with frequent feeding needs.

Early sleeping habits are assisted by parents who gradually bring their baby's natural sleeping patterns round to fit in more with their day and night-time routines. In the first year of life most babies move from having several periods of wakefulness followed by sleep over the course of the day and night, to having three regular sleep periods (the longest overnight with a morning and afternoon nap). The morning nap is often dropped shortly after the first birthday and the afternoon nap around the age of three.

Sleep and night-time behaviours have a cultural base too and the habits and preferences vary in individual families and different cultural and social groups. For example, some groups expect their baby to sleep in a separate room at a much later age than other groups.

Some specific sleep problems have however been observed to occur in a small proportion of children who do not have light perception or have retinal problems. Either as babies or during their second year (ie at one to two years of age) they may reverse day and night, sleeping only two or three hours overnight and having periods of sleep and wakefulness throughout the day. The reason for this change at this particular age is not yet understood, but most children do eventually re-establish a more acceptable day and night routine.

Limited visual stimulation sometimes means babies are less active during the day and are not ready for sleep at bedtime. This may be of particular relevance between the ages of one and two years when children usually become mobile and very active. Children are equipped with lots of mental and physical energy to enable them to move around and learn about their world. If their movement is restricted (for example by visual difficulties) this excess of energy may prevent sleep at bedtime and result in tiredness and napping during the day.

The human body is designed to be awake during daylight and to sleep when it's dark. Children with limited light perception may have difficulty distinguishing night from day and in adjusting their body clock to day and night patterns. Anyone who has travelled across time zones and has experienced 'jet lag' understands how the body gradually adjusts to new day and night patterns over a number of days. This is partly a matter of adopting new daily routines but also of the body adjusting its chemical messages, produced in response to daylight, about when you should be awake or asleep.

Melatonin is a hormone produced in the pineal gland. It responds to dark and light as a result of retinal stimulation. It's produced in the hours of darkness, has a mild sedative effect and lowers the body's temperature while asleep. It's responsible for setting the 'body clock' and without it, a twenty-five hour cycle is sometimes adopted. Melatonin is available as a medication on special prescription, but there are only limited studies about its use in children.

In some studies melatonin has been found to be effective in helping to establish a day and night sleep pattern, but this is not yet fully established scientifically. More studies are being done to find out about how useful and effective it is in different children and any possible side effects.

Moving on

- The Developmental journal (Towards independent self-care: Establishing a bedtime routine and sleeping pattern) shows what may be developmentally possible at each stage, even though expectations and requirements may vary in different families. The Activity cards (Towards independent self-care) give suggestions for setting up positive sleep routines.

Signposts to extra help

If having tried the strategies suggested on the Activity cards, your child continues to have night-time waking and persistent sleep problems, consult your GP or paediatrician for advice. This is also advisable if your child cannot distinguish day from night because they have no light perception. As well as medical help, you may need advice on behaviour modification and sleep techniques from a health sleep advisor or a clinical child psychologist.

Language issues

Echoing (Echolalia)

Repeating or echoing what other people say is a stage of development that all young children go through. It's a way of practising speech and learning about language and communication. It is often prominent in children with limited vision and in some children may persist as the main speech pattern well beyond 18 months. This is particularly the case in children with the most limited vision.

All babies and toddlers practise speech sounds by copying what others say. This may be single sounds or sound combinations, single words, or whole phrases. Often intonation or tone patterns are copied, too.

Children may also repeat what adults say to stay in touch and take their turn in the conversation and this is more common in children with very limited vision. Repetition may be used to mark the beginning of a conversation or to keep the conversation going. As the child starts to have some understanding of words and phrases, they may still rely on repetition to help get their message across in early verbal communication. For example, they may repeat a single word 'drink' or a phrase like 'want a drink?' – if trying to communicate that they want a drink.

Some children with limited vision get rather 'stuck' in the echoing stage. Frequent echoing of immediate phrases or delayed language (that is, snatches of conversation heard previously or language from TV, the radio etc) continues longer than would be expected in typical development. This is called echolalia. If this is persistent, you may want to try some of the following ideas.

Check first

- The first stage of repeating sounds, words or phrases usually appears by Stage 2 in the Developmental journal.
- Ideas are given on the Activity cards under Communication, language and meaning to help the development of wider language and communication skills.
- If your child is having difficulty moving on, then you may find it helps to go back to earlier cards and ensure that previous skills are well established.

Moving on

- Simplify your language input to your child. They may be having difficulty understanding your words and phrases. Use shorter sentences and clear, simple language, like 'Sit down', 'It's bathtime', 'Shoes – on'.
- Give only one idea at a time – 'ball' or 'push'.
- Offer choices, so that your child has to make a definite response.
- When you talk to your child, be very careful to link each word or phrase to a specific object, routine or activity, so that it has clear meaning.
- Make concepts concrete, so that whatever is talked about is specifically linked to the actual object, event or person in the 'here and now'.
- Talk about and explain what's happening to your child, being careful to link this language to what they're experiencing.
- Use ideas for shared discovery and joint attention, eg guiding hands to help your child understand that you are sharing the same focus of attention. This is important for achieving a shared understanding and meaning of language.

- Help your child to communicate with purpose. Respond if they try to indicate something that they want or need – through action, gesture or language.
- Don't encourage your child to express repetitive 'party pieces' which get encouragement and attention from other people, such as counting numbers, saying letters of the alphabet, singing nursery rhymes to visitors. These all encourage imitation of language, relying on learned and memorised expressions, and the use of language without any clear purpose.
- If the above ideas do not seem to help your child, you may need to go back to the earlier stages of social interaction and social development and language and communication. Your child may need more time to lay the foundations of social interaction and communication. See Social and emotional development and Communication, language and meaning in the Developmental journal (especially Stage 1b and then Stage 2) and all the associated Activity cards.

Signposts to extra help

In some children, echolalia continues to be persistent and frequent and more meaningful language does not develop or is infrequent. This may indicate that your child is developing language more slowly or is having difficulty in developing communication skills. It would be advisable to consult a speech and language therapist who can give you specialist help, if this is the case.

Behaviour issues

Resistance to adult direction

Many young children go through a stage of being resistant to adult direction and guidance. This is what parents sometimes talk about as the 'terrible twos' though it can start before or after the age of two and may go on long after the two-year-old period. Though difficult for parents, it's generally a positive sign that a young child is beginning to be more independent and self-directed. They're beginning to have strong wishes and intentions and will take action to achieve their goals.

With their growing awareness of what they want to do or have, children can become highly frustrated if their wishes or intentions are thwarted. They may also get very frustrated if they can't communicate what they want. This can quickly lead to crying, screaming and kicking or struggling and may erupt into a tantrum. A young child cannot easily regulate their emotional state and once upset they may be very difficult to calm down and console.

Although young children begin to show some independence, they still need to feel that their parent is in control. They need to know the limits of behaviour, routines and activities – and where the 'boundaries' of acceptable behaviour are. Without strong parental input and limits, the young child will feel 'out of control' and insecure.

Young children with limited vision also go through this stage of increasing independence and self-direction. The period may last longer or the tantrums may be more intense. This may be because children with limited vision find it harder to communicate their wishes and therefore feel greater frustration. It can also be more difficult to help a child regulate their emotions and to calm them once very upset. This period can be difficult for parents because they feel cut out of the child's world. They can't show their child how to do things or what is expected when their child is resisting all adult guidance and direction.

If your child is very independent and self-directed or having frequent tantrums, you may find the following ideas useful:

Check first

- Consider appropriate behaviour expectations for your child's level of development and understanding (see Social and emotional development: Behaviour and self regulation) and look at advice on the linked Activity cards.
- Look at further ideas in Communication, language and meaning: Joint attention to toys/objects, especially at Stage 2. These give ways of helping you and your child do things jointly, while helping your child lead and share their focus of attention. This is a valuable foundation for communication of wishes and intentions, especially before language has taken off.

Moving on

- Keep everyday routines and activities as regular and consistent as possible, so that your child can anticipate what's going to happen next, how and when. This helps children feel secure and in control and to predict the pattern and changes of the day.
- Make routines and activities pleasurable and fun so that your child enjoys participating in them. It helps to make joint games out of everyday activities.
- If your child is very resistant to being directed, find an activity they really enjoy and use this to motivate joint play. Play near your child, so they know you're there. Use a guiding hand, shared discovery and/or a joint attention approach. This helps you to be involved without your child feeling that you're taking over. They may then gradually let you join in more actively.
- Try to keep firm instructions and handling to the minimum so that you're not setting up a conflict situation.

- However, maintain definite boundaries and limits within what is appropriate for your child's level of development and understanding. Communicate them clearly and try to stick to them consistently.
- Try to anticipate if your child is getting tired, frustrated and irritable and change the situation before your child starts getting distressed or angry. For example, they may need a 'quiet time' or rest time or a relaxing activity like listening to music tapes.
- Give your child enough time and space to explore and develop greater independence and exploration. Encourage them to show more independence and self-help during everyday activities like feeding, dressing, bathing.
- Avoid shouting and don't smack or hit. Try not to get angry with your child, but stay calm and firm if they start building up for a tantrum.
- If your child starts having a tantrum, calmly move them away from the source of frustration. They may calm down gradually as they're moved away from this area or activity.
- If they start kicking, screaming and hitting, keep them safe from hurting themselves or other people. It can be helpful to put them in a quiet, safe environment and to give them time and space to calm down gradually. It's advisable to stay close by for safety reasons, but avoid giving positive attention until they've calmed down. Some children are calmed by being held, some are not.
- Give plenty of praise to appropriate and positive behaviours.
- Show your child calmly what are unacceptable or negative behaviours – eg first, a firm 'No', then a simple explanation, then removal from the situation. Distraction to something more interesting is also useful for avoiding a build up of conflict.

Signposts to extra help

Some children continue to be resistant to adult direction and tantrums may continue at a frequent level. It can feel very difficult to steer your child into different activities. If this is the case, it would be advisable to seek the advice of a paediatrician or clinical psychologist who can advise on behaviour problems.

Resistance to change

Most young children have difficulty moving from one activity to another during some of the early developmental stages. This is part of normal attention development, when they learn to control their attention and fix on one focus of interest (single-channelled attention), but find it difficult to attend to more than one thing at a time or to shift attention from one focus to another.

If they're engrossed in doing an activity, they may find it difficult to listen to a parent talking to them or to respond when a parent tries to introduce a new activity. This period of attention control also tends to coincide with the stage when children are becoming more independent and self-directed. They may not have the communication and language skills to express that they want to continue with what they're doing. They can get very frustrated if someone tries to shift their attention to another object or activity.

Young children with limited vision tend to be more resistant to change than fully-sighted children. This may be something to do with the role of vision in attention shifting and going from the known to the unknown. Children with limited vision don't have added visual clues to see what's coming next and motivate them to start the new activity. They also don't have the visual stimulus of the new activity to help them release and shift attention and move on to the next thing.

Check first

- Look at the Developmental journal and Activity cards on Communication, language and meaning: Listening and Attending, for ideas on how to help your child's use of attention at their current level of development.
- It is a good idea to also refresh your knowledge of the ideas on the Activity cards for Behaviour and self-regulation (under Social and emotional development).

Moving on

The following gives ideas for helping your child make transitions more easily:

- Keep everyday activities and routines in a consistent pattern or order so that your child can predict and anticipate what's going to happen next when they finish each daytime routine.
- Prepare your child for change. Give them a warning about change by saying things like 'When the song finishes we will…' For the child who does not yet understand language, this can be through an object which indicates what's going to happen next (eg give a bib to indicate dinner time is coming, or put outdoor shoes on for going out).
- For the child who doesn't yet understand language, keep a consistent object or activity to mark the beginning of the next activity. Objects like this are called objects of reference. For example, a bib or spoon for meal time, a plug and chain for bath time, a ball to indicate going to the playground. Choose an object that refers to or represents the particular activity. Give the object of reference to your child to hold, just before you start the appropriate activity. This gives them some preparation and helps them anticipate what's going to happen next. Encourage your child to hold the object of reference and take it to the start of the new activity.

- You can help your child find the object of reference – for example, to go to collect the spoon for meal time. Keep objects of reference in one box in a set location so that your child knows where to find it each day. This helps them feel more in control of the transition from one activity to the next.
- Keep the transition time short so that your child doesn't have to wait long before the next activity begins.
- If your child is upset about leaving an enjoyable activity, make it clear where you've put the activity that they're leaving (eg put a toy in toy box) and that they can come back to the activity at a later time ('after lunch' or 'When we come home again').
- Use concrete language to explain – eg 'When we get home', rather than the vague term of 'later'. Using a timer may be helpful. Say 'When the bell goes, then it's time to go to the shops and finish playing with the keyboard'.
- Introduce something interesting that will attract your child, before you remove something else, so that they're motivated to move on to the new activity. This is called fading out a previous activity.
- Give your child something favourite to take with them when they go out or go on a car ride – for example, a special toy or tape. It's quite a good idea to vary the toys or objects so they don't get fixed on one object that always has to be with them.

Signposts to extra help

If your child continues to be very resistant to transitions and the above suggestions have not led to an improvement, it would be advisable to seek specialised help, such as that of a paediatrician or a clinical child psychologist who can advise on behaviour problems.

Repeated or repetitive behaviours

Children with limited vision may develop repeated or repetitive behaviours, such as regular body rocking, waving their hands in front of their eyes, flapping hands or swaying their head or body. They may bang an object on the table over and over again, or keep on opening and closing a door, or flick a string of beads repeatedly.

Some children repeatedly poke or press their eyes (eye poking is especially common in children with eye conditions affecting the retina). It's thought to lead to pleasant visual sensations.

These behaviours have been referred to as 'self-stimulation' because they don't seem to have any other purpose than self-comfort or pleasure or simple brain stimulation. All children and adults without any visual difficulties show examples of self-stimulation behaviours, such as hair twirling or flicking, humming, tapping a foot, drumming their fingers, or doodling with pen and paper. People participate in these activities because they find them pleasurable and comforting. They're thought to occur more when people are bored or lacking in purposeful activity. They are also believed to be calming, especially if a person is anxious or stressed.

These behaviours may seem socially unacceptable, because of their inward or introverted quality and they can become a habit that is difficult to change, like thumb sucking or nail biting. They may also get in the way of children having more appropriate interactions with objects and people.

Why are these behaviours common?

The reasons for their frequency in young children with limited vision are not definitely known, but the following possible reasons have been suggested:

- young children with limited vision are less mobile and may resort to these behaviours to expend energy
- they may not have sufficient experience of movement and of feeling their bodies in different positions in space
- they may feel more anxious and become over-aroused
- young sighted children can see things to do when they need a change of activity or stimulation and can move on to another activity. Children with limited vision do not easily see what else there is to do and may lack stimulation and be bored
- repetitive behaviours are also found in children with learning difficulties and some children with limited vision have additional learning difficulties
- children with sufficient vision are able to see themselves or others doing these behaviours and can learn whether the behaviours are socially acceptable or not, but a child with limited vision may not understand whether they're socially acceptable or not.

Children usually grow out of many of these behaviours naturally as they mature and learn to interact with toys and people in more satisfying and stimulating ways. Understanding what stage your child is at (using the Developmental journal) will help you to know what activities could be introduced to help your child move on. Nevertheless, there are useful ways of helping to reduce these behaviours, which may help stop them becoming habits.

Moving on

- Gentle correction. Gently touch your child to stop them rocking or remove the hand that is eye poking and give them something else to do. Try and do this consistently, whenever you see the behaviour.
- Don't keep telling off and nagging. Try not to bring too much attention to these behaviours, as your attention might positively reinforce and increase the behaviour.
- Never get cross or smack your child. They can't help doing these things and are not being intentionally naughty. Your attention to their behaviour may reinforce it. Also, you may make your child more upset and anxious, which tends to increase repetitive behaviours.
- Remember to give attention and positive reinforcement (like praise, a cuddle, a reward) when your child is engaged in more purposeful play activities. These are the behaviours and activities you want to encourage.
- Think about what sensory information your child is seeking or craves and offer this through alternative and more acceptable means. For example, if they like to rock and spin, they may enjoy playing on a swing, spinning in a tyre or rocking equipment. Keep these activities short and join in with the activity, to make it social – for example, singing an appropriate song while they rock or swing.
- Give alternatives. Channel activities into something more productive – for example, banging a stick repetitively on a table could be turned into banging on a drum.
- Join in and make the play less isolated. In a child who enjoys flicking or banging objects repetitively, join in play with the object, recognising that it's fun for them. You could then modify the way that the object is used to try to extend the activity into something more meaningful for learning, like taking turns to bang, and then taking turns to make a tune on the xylophone.
- Change the surroundings in which the behaviour occurs, so that it opens up new experiences.

- Give your child constructive toys which they can manipulate in the same way as their repetitive behaviour or at the same developmental level. For example, a child who repeatedly opens and closes doors can be helped to open and close a music box with a hinged door, with the cause-effect learning of making music. Keep the play activity short so that it doesn't become another repetitive behaviour.
- Shift attention to some other activity. Give your child an alternative toy to keep their hands or body occupied.
- Maintain a daily routine of activities and experiences so that your child is not lonely or bored.
- Check when your child is playing alone. If your child is doing the same thing over and over again, show them another thing that they can do when they're playing on their own, eg if spinning wheels of a truck, fill it with crisps or savoury snacks – something that they enjoy eating, and show them how to dump them out of the truck.
- Passive activities such as watching or listening to TV or videos and music tapes may lead to your child engaging in a repetitive habit. Try asking questions about what they're watching after a time, or join in singing to the tape and encourage your child to sing with you. Make sure that your child is not spending too long with these passive activities on their own.
- Leave a consistent quiet time in the day when your child is given the opportunity for calming behaviours, such as rest time after lunch. This helps children start to learn that there are acceptable times for private self-stimulatory behaviours. Later you can introduce a fiddle ball or other more appropriate behaviours.

Signposts to extra help

If these behaviours are very persistent and do not get less over time and are interfering with your child's learning and exploration of their surroundings, then you would be advised to seek further help from a specialist teacher for children with visual impairment or an occupational therapist. Advice from a paediatrician or clinical child psychologist may also be helpful.

Learning, social and communicative difficulties

All children develop at different rates with some children developing slower or quicker than others. The rate of development is also often uneven, with some areas of development moving along faster than others. In any area of development, the rate of learning can be uneven with development moving along in sudden spurts and plateaux rather than at a steady rate all the time.

This varied rate of development is even more marked in children with limited vision, with considerable variation between different children. In general, the children with the more profound levels of vision loss also develop most slowly, although there are individual children with profound vision loss who develop quickly. Likewise, there are children with severe vision loss who develop more slowly, even though their visual development is moving along quite well.

Developmental setback

The work of the Developmental Vision Team (Great Ormond Street Hospital) and other groups has found that some children who have limited vision get into difficulty in their general development in their second to third year of life. They do not appear to make the expected developmental progress and may not move forward over 6 to 12 months or longer. This may affect some or all areas of their development. Sometimes they appear to go a little backwards – for example, they stop speaking any words after initially having a few words or some basic language. The Developmental Vision Team refers to this apparent slowing down or going into a long plateau as a developmental setback.

There are quite a few signs of possible developmental setback. All these behaviours are part of normal development, but if they continue and don't change over a year or longer, they can be signs that the child is having some developmental difficulty. These can include temper tantrums and unwillingness to be guided by the parent or adult. Other signs may include becoming very self-directed and avoiding social contact. The

child may have difficulty communicating and using language, and if they speak, it may often be echoing or repeating things that they've heard earlier in the day or previously. Play may become rather repetitive, eg always playing with the same toy in the same way, or using objects in non-functional ways such as banging it on the table or fiddling with a part of the object such as a chain. The child may become very involved in self-stimulatory actions, like frequent rocking or head-banging or eye poking. They may be hypersensitive and/or avoid certain sounds or textures and become agitated if brought into contact with them.

Signposts to extra help

Any of the behaviours described here may occur during normal development and the previous sections give ideas for helping your child move on with any of these 'sticky' areas.

However, if they persist over a long period and continue to be intense, then your child may be experiencing a setback in their development. It may also indicate that your child has possible learning or social communication difficulties that need to be investigated.

It's very important that you get further specialist help as soon as possible and at your earliest concern. Your GP or consultant paediatrician or ophthalmologist can refer you to a health team, which specialises in child development and visual impairment and can help with diagnosis and intervention. It is helpful if the team includes a developmental paediatrician, a clinical or neuro-psychologist, a speech and language therapist and an occupational therapist. Some specialist teams also have a specialist teacher for visually impaired children involved. Extra specialist help can be set up to help you and your child.

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