

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

Advice for Connexions PA/other professionals



Heather Murdoch and Eileen Boothroyd

Sense is the leading national charity that supports and campaigns for children and adults who are deafblind. We provide expert advice and information as well as specialist services to deafblind people, their families, carers and the professionals who work with them. In addition, we support people who have sensory impairments with additional disabilities.

Contents

- 4 This booklet
 - 5 What is transition?
 - 6 What happens at this time?
 - 7 Who is involved in transitional planning?
 - 9 What should transition planning cover?
 - 12 Thinking about what your son or daughter wants
 - 14 Thinking about what you, as parents, want
 - 16 Finding out about the options
 - 23 Making a transition plan
 - 26 Putting plans into action
 - 27 Transition timeline
 - 29 Transition profile
 - 38 Contacts with professionals – recording charts
 - 40 Resources
-
- 43 Information for Connexions PA/other professionals
 - 49 Transition planning meetings – making it work for msi young people

This booklet

There are many transitions in most people's lives – starting school, moving house, getting married, changing jobs and so on. Periods of change can often be difficult, but being well-informed, and knowing what you want to happen, can help a lot.

This booklet is designed to guide you through the transition from school to the world beyond. It deals with the period from age 13 to 19 or later when young people plan and begin their future as young adults. For students with disabilities who require continuing support, the process is especially complex because of the move from children's services to adult services.

This booklet is written for parents and other family members. It describes what happens during transition for young people with MSI (multi-sensory impairment / deafblindness) who have Statements of Special Educational Needs (SEN). It is designed to help you

- think about what you want and what your son or daughter wants;
- record your ideas;
- work with professionals to make transition as smooth and successful as possible for your child.

It includes a section written for Connexions Personal Advisers (PAs), who manage much of the transition process, and who often have little or no experience of multi-sensory impairment. From 2010 the Connexions Service became part of Local Authorities (LA).

It also lists useful organisations, websites and other resources which you may find helpful.

What is transition?

Transition, in this context, is about moving from childhood to adulthood. It involves changes in every aspect of life. Adolescents change, physically and emotionally; they move from school to college or work; they learn to manage their own money and social lives. They may leave home, get a job, find a partner and get married. Some of these changes happen to everyone (leaving school, for example); others are personal choices.

For young people with multi-sensory impairment (MSI), the transition to adulthood is just as difficult. They face particular challenges – it is harder for them to develop independent social lives, for example. Nevertheless, the issues which face them are the same as for any adolescent: what to do, where to live, what to do for money, how to get a good balance of freedom and support.

Adolescence can be a stressful time for families, as every parent knows. When a child has complex special needs and continues to need a lot of care, the move to adulthood can be even more stressful. In addition, you may not be sure what your son or daughter wants to do after leaving school, or what support is available for adults with complex needs. You may need to help make huge decisions about your son or daughter's future, with the knowledge you have, on their behalf. This booklet is designed to help you think about what the future may hold and to find the information you need.

What happens during this time?

In principle...

In the past, adults with MSI were expected to fit into the services provided for those with disabilities. Transition involved finding the best available service and funding it. Personal choices were often very limited.

Good practice in transition planning now emphasises person-centred planning. This means identifying the young person's needs and wishes, and developing an individual plan for their future using a range of agencies and services, such as social services, health, further education, housing, leisure and employment. Wherever possible, community facilities are used with the help of specialised support. This support may be provided by social services or another agency, or it may be decided by the young person and/or their family.

In practice...

As with any complex system, transition planning sometimes works well, and sometimes does not. Many of the strategies and procedures in current practice have been introduced very recently, and adjustments are still being made, so that professionals are coping with considerable changes. There is general acknowledgement that the coordination of services can sometimes be poor, and that the wishes and concerns of young people and their families are not always handled well.

When the process works well, on the other hand, young people with MSI can achieve a way of living which they have chosen or helped to choose, which meets their needs and gives them opportunities to continue to develop their aspirations and lifestyle. The young person at the centre of the plan should have his or her voice heard – and this should be facilitated.

Always remember that you, as parents, know your child better than anyone else. Your input to your son or daughter's transition to adulthood should be welcomed by those planning and providing services. If at any point you feel that the process is not working well, or that aspects of planning have been overlooked, say so. Professionals may not realise what is important to you and your family until you tell them.

Who is involved in transitional planning?

Your son or daughter is the most important person in the process, and should be as involved as possible. Remember to ask for this to be facilitated if communication or other support are required.

You and the rest of your family are the next most important. Transition planning should consider your wishes, needs and capabilities when looking at the options for your son or daughter.

Connexions Personal Advisers (PAs) usually work with young people aged 13-19, but can be involved until a young person reaches twenty-five. Their role includes

- helping young people to plan their future,
- co-ordinating assessment,
- liaising with other agencies, and
- overseeing delivery of the Transition Plan (the programme of action relating to transition).

Connexions PAs will not be specialists in MSI, and may have little experience or knowledge of complex needs. They are specialists in the planning process, and should be able to work with you and the professionals involved with your child to understand and provide for your son or daughter's needs. PAs may be based in schools, colleges or community settings, so that your child's PA may well change when they leave

school. Because MSI is so rare, and creates such complex needs, you may want to ask the school and Connexions service if one person can act as transition coordinator throughout the process.

There is a section at the end of this booklet designed for use by PAs and other professionals – you may want to give your child's PA a copy. You could also suggest that they contact Sense for more information.

Your son or daughter's school will begin the transition process. The headteacher will invite the Connexions PA and other relevant professionals to your child's Year 9 Transition Planning meeting (usually the Annual Review meeting). The head is also responsible for drawing up your child's Transition Plan. **School staff** will bring detailed knowledge of your child's needs and abilities to the planning process, and will teach any new skills or knowledge identified in the Transition Plan.

The Local Authority – Education Department liaises with the Connexions service before your child starts Year 9. The LA also maintains your child's Statement of SEN (subject to the usual reviews) until your child leaves school or reaches the age of nineteen.

The Social Services Staff are responsible for carrying out a Community Care Assessment to identify the support your child will need

as an adult. They have specific additional responsibilities towards:

- young people with deafblindness;
- young people attending residential schools; and
- those looked after by the local authority.

As carers, you are also entitled to an assessment of your own needs.

Someone from Social Services must be invited to the Year 9 Transition Planning meeting.

The Health Authority's involvement depends upon individual medical needs – for example, for speech therapy or physiotherapy to continue into adulthood.

Other agencies may be involved depending on individual circumstances.

Further detail of what each agency offers, and how it offers it, is given in the section 'Finding out about the options'.

You may want to keep a list of the professionals you meet, and a log of your contact with them (especially phone conversations). Charts for these are given on pages 38 and 39.

What should transition planning cover?

It should cover **everything to do with moving to adulthood** – for example:

- independence
- relationships
- housing
- employment
- education
- money
- health
- advocacy
- leisure and social opportunities
- transport

Too often, transition planning for young people with MSI still focuses on how the move to adult services will be managed, rather than the move to adulthood. Even within this focus, there is often a strong emphasis on planning further education. Other issues, such as transfer to adult health and social services and benefit entitlements, may be ignored.

You and your son or daughter should be setting the agenda for transition planning. Be prepared to speak up if you feel that topics you think are important are not being covered, or if you think some areas are receiving more attention than they need at the expense of others.

The chart overleaf may help you to decide which areas you think are most important. Not all the topics above will be relevant for every young person. One yardstick is to consider whether your child's special needs (or other people's perceptions of them) may make any of the areas mentioned harder to achieve. If they do, then the topic needs to be included in planning. You may want to give copies of the completed chart to the professionals involved, so that they have a record of your priorities.

Transition planning for



Topic	I think this topic is:			Specific aspects I want's transition plan to cover (circle those you want and add any others)
	very important	fairly important	not very important	
independence				safety and risk; access to information; healthy living; making choices;
relationships				maintaining friendships; making new friends; sexual relationships;
housing				living with family, alone or with others; support needed for care and daily living; privacy; adaptations and equipment needed;
employment				supported or open employment; work placements; work-related training; support, aids and equipment needed;
education				further education at school and/or college; whether provision is specialist or generic; whether provision is day or residential; courses of interest and support needed;
money				wages and/or entitlement to benefits; managing money; the direct payments system;

Topic	I think this topic is:			Specific aspects I want's transition plan to cover (circle those you want and add any others)
	very important	fairly important	not very important	
health				moving to adult services; medical and/or nursing support; speech therapy, physiotherapy, occupational therapy; provision of hearing, visual and other aids; changing medical needs;
advocacy				parents or others as advocates; self-advocacy; circles of support;
leisure and social opportunities				religious or cultural activities; sports; music; hobbies; clubs
transport				mobility; use of public transport; road safety;

Completed by: _____

Date: _____

Copies of this chart can be given to the professionals involved in transition planning, to ensure that the topics important to you and your son or daughter are covered.

Thinking about what your son or daughter wants

The guidance for professionals involved in transition planning is very clear that the young person's needs and wishes should be at the heart of the process, and that the young person should be involved in decision-making. Many young people with MSI face two particular difficulties with this:

- they find it hard to think and communicate about events beyond their experience;
- they lack the information needed to make real choices.

Some ways of addressing these problems are outlined below. A more detailed version is given in the section for Connexions PAs near the end of the booklet.

Making informed choices

Most children become aware of a range of careers as they grow up. They know what their parents do; they see teachers, sales staff, builders and others at work around them; they see people on TV doing various jobs. Young people with MSI may have some ideas but do not always have this kind of knowledge in detail.

Most young people with MSI need to actually try things out in order to learn about them. Your son or daughter is likely to need repeated visits or a trial placement at a college, group home, club or other setting before they can decide whether or not they like it – and certainly before other people can make decisions on their behalf.

Your child's responses to one setting – what they do and don't like about it – will help to suggest other possible options.

Expressing choices

Most young people with MSI communicate much better with people whom they know and trust. It is vitally important that your child talks about transition with such a person – whether through speech, sign, symbols, gestures or body language. Some young people with MSI may clearly communicate choices or express a preference by their behaviour in different settings.

Sometimes, young people with MSI may make choices that seem unrealistic. Try to think through what support and skills the young person would need in order for their wish to become reality. If it can be done, then person-centred planning should support the young person in doing it.

Changing needs

Some young people with MSI have changing needs, because their health, vision and/or hearing continue to change. Adolescents with Usher syndrome, for instance, may find that their poorer night vision limits their social lives just when their peers get more freedom. Transition planning may be the first time that the young person has had to face and plan for the reality of changing abilities. They may find this very difficult. Parents and professionals will need to

respect the limits of the young person's ability to face change if they are to stay at the centre of the planning process.

Young people with Usher syndrome or other changing conditions may have career plans which seem unrealistic to adults around them. These need careful thought. Is the plan really unrealistic? Very few people have careers for life these days; think hard about the possibility of changing track later.

Profiles or passports

Some young people with MSI have very limited formal communication. Family members, professionals and friends need to share their knowledge of the young person to find out what may be important to him or her in adulthood. One approach is to develop a transition passport or profile. This is an account of a person's

preferences and needs, written from their viewpoint.

The example here (page 29) suggests some headings that might be included in a profile for your son or daughter. The detail for each heading might be in written words, photos, video or whatever seems most appropriate. The profile can be used as a basis for discussion at transition planning meetings, especially if your child cannot contribute directly to the conversation. It can also be passed on when your son or daughter begins a new placement, to help new staff to get to know them more quickly.

Your child's school will probably be using approaches like this already. Staff at school are likely to ask you to contribute your knowledge to profiles or passports. If they do not, you may want to suggest ideas, or to keep a record at home that can be used with others in planning.



Thinking about what you, as parents, want

Parents are often so anxious to get their children's needs met that they forget to take account of their own needs. Although your child's wishes are central to transition planning, they have to be considered in the context of your needs too. Your child may want to continue living at home and be cared for by you, for example, but your health may not allow this.

It is important to recognise that this stage of your child's life can make great demands on you. It can be hard emotionally for any parent to see their child becoming an adult, and especially so, when that child still needs high levels of care and or support. There are also new demands from external services – new support systems to learn about and new professionals to engage with. The professionals you meet should be sensitive to these issues and should offer support when appropriate.

A move away from home should always be discussed and considered. With the right support, all young people can enjoy a new lifestyle, develop new skills and interests and meet new people. This is all part of growing up. There are many ways of achieving greater independence and now is the time to begin to think about the broader picture and the longer term future for your whole family. This can be challenging for everyone but planning now can provide peace of mind later.

Making the right financial arrangements, as you grow older, is one of the issues that parents worry about most. There is no single correct answer as each family will have different requirements.

Increasingly, families, with a young member who is unable to handle his own financial and legal affairs, choose to set up a Trust in a Will. This aims to protect that person's interests if anything should happen to you. Including a properly structured Trust in your Will may make the difference between seeing all of your assets devoured by the local authority within a few years, or making a long lasting difference to the quality of life of your son or daughter. So, taking this action can guarantee continuity and security of care and also provide for some of the extra things, like holidays and equipment that you would want to be readily available. (See the Resources section on page 40).

You may find it helpful to talk to other parents, perhaps with slightly older children. Contact Sense for help with this if you want. You might also want to seek advocacy support – see the Resources section for helpful organisations.

What are your aspirations and hopes for your child as they become an adult? Try not to let your thinking be limited to the provision you know is available. Think about the help you and they receive now, about what should continue and what should change. Pin down the detail of your hopes – the clearer your vision of the future; the easier it will be to explain it to other people.

You may want to use the chart over the page to list the things you want to happen and the information and support you need from others. It may be useful to give a copy to the professionals involved in helping your family, so that they know what sort of help you want.

Parents...

What I want for in adulthood	Any further information needed about this	Support needed for this to happen

Finding out about the options *and* making a transition plan

Transition planning is a lengthy process, beginning when a young person is thirteen and continuing until they are at least nineteen (see the Transition Timeline on page 27 for an outline of what happens when). This should allow plenty of time to explore all the options available, to make informed choices and to prepare the young person for change. Also to avoid delays in the process.

Connexions PAs are responsible for

- co-ordinating assessments
- liaising with other agencies and
- overseeing delivery of the Transition Plan (the programme of action relating to transition).

They can refer the young person to specialist advisers such as Sense staff for assessment and advice.

Gathering information

You should be given information about every aspect of the transition process. In practice, many parents have sought information for themselves, contacting agencies and individuals directly. You may want to contact your Sense Office to find out about local provision used by other people with MSI – you don't have to choose the same options for your child, but it will give you a basis for comparing other services.

Many parents have found talking to other parents about transition, and belonging to organisations such as Sense, very helpful.

Information on other sources of help and advice should be available from your child's school, the LA, the Parent Partnership Service or Connexions.

It is useful to keep notes, with dates, of your conversations and phone calls with service providers and other professionals. At busy times a diary will help you to record what people are doing. It will also provide a record of events. A chart for this purpose can be found on page 39.

Services for young adults with MSI

The main agencies providing services to adults with disabilities are

- local authorities, including education and social care departments
- Health Trusts
- Further education providers funded by Learning and Skills Council (and from 2010 the local authority or in some case the Young People's Learning Agency (YPLA))
- the Employment Service
- the voluntary sector
- Connexions and the Careers Service at the LA

Young adults with MSI are likely to receive services from almost all these agencies. In theory, different agencies should coordinate their input. In practice, this is made more difficult by different structures, assessments and criteria for providing services.

The Department of Health has produced a White Paper on learning disabilities called Valuing People. It says that people who make ‘substantial and long term use’ of services should have a **named person to coordinate the services they receive**. If it is clear that your son or daughter will fall into this category, ask who their named person will be. Check that this person (and anyone else who will influence the services your child receives) is familiar with multi-sensory impairment and the needs of those with MSI. If not, Sense can provide information and advice.

(Even when services claim knowledge and experience of multi-sensory impairment or deafblindness, check what they mean. The majority of deafblind people are elderly and have acquired deafblindness after many years of full hearing and/or sight. Their needs are very different from those of young people who were born with MSI.)

Some of the agencies listed above provide more than one service, and some services are provided by more than one agency. The rest of this section is organised by services: social services, education, health, benefits, housing and employment.

Things to ask your child’s PA:

- **Who is the person responsible for coordinating the services they receive?**
- **Does this person understand the specific needs of people with MSI?**

Social Services

A social worker must attend your son or daughter’s Year 9 Transition Planning meeting, because they will be eligible for a **Community Care assessment**. This identifies what services, if any, they will need in adulthood. These services must be provided from the age of eighteen, and Valuing People stresses that the Community Care assessment should be carried out well before this age. **Carers are entitled to a separate assessment** of their own needs, which may lead to further services.

Care services may be provided by the local authority, or arranged by the young person or their family using the money from **direct payments**. Direct payments must be spent on support to meet assessed needs. They can be used for many different forms of support – for example, individual support to access leisure facilities or college courses, short breaks or housing-related support – but not for residential care.

The care services or direct payments provided will depend upon assessed levels of need and on where the young person will live. Services may not be full-time. They should emphasise preparation for employment or lifelong learning, and be individually designed around the young person’s preferences. External factors such as shortages of qualified staff may limit the options.

Social Services departments have further duties to people with deafblindness under the local authority circular 'Social Care for Deafblind Children and Adults'. (This guidance only applies to people with dual sensory impairments, not to those with hearing or visual impairments and other disabilities.) Local authorities must identify, contact and assess people with deafblindness, and provide appropriate services, including specially trained one-to-one support workers if necessary. The assessment of needs must be carried out by people specifically trained in deafblindness. This guidance applies to children as well as to adults, but if your son or daughter has not been assessed under the guidance in the past you may want to start the process at transition.

(Some local authorities have implemented the guidance more successfully than others. If the local authority does not know about it give them the Sense website address www.sense.org.uk)

Local authorities may **charge for any services provided**. Government guidance spells out what income they can and cannot take into account when deciding how much to charge. Overall, they must leave the individual with enough income to meet basic needs and the extra costs of disability.

Social Services departments have special responsibilities towards **young people looked after by the local authority and those attending residential schools**. These must have Pathway Plans which build on previous Care and Personal Education Plans. Social workers must maintain contact and support for young people who have been looked after by the local authority until they reach the age of twenty-five.

Things to ask your child's social worker (or PA):

- **When will your child's Community Care assessment happen?**
- **Which professionals will carry out the Community Care assessment? Do they understand the specific needs of people with MSI?**
- **(If you want:) When can they arrange an assessment of your own needs as a carer?**
- **(Under the local authority circular 'Social Care for Deafblind Children and Adults') When can they arrange your child's assessment in accordance with Social Care for Deafblind Children and Adults?**
- **Who will carry out this assessment? What training have they received in MSI?**

Education

People with multi-sensory impairments tend to learn slowly and to have gaps in their knowledge because MSI limits the information they get. Because of this, most young people with MSI benefit from continuing their education past the minimum school leaving age.

Young people with MSI can:

- stay on at their current school if it offers post-16 provision;
- transfer to a different school or to college;
- go to college after an extended time at school.

If they continue their education at a school:

- their Statement of SEN is maintained, subject to reviews as usual, until they are nineteen;

If the young person leaves school and goes to college:

- their Statement of SEN ceases. The college they attend will become responsible for meeting their special educational needs.

The Connexions PA is responsible for developing an assessment profile of your son or daughter (sometimes called a **Section 140 assessment**). This profile is usually completed during your child's final year at school. It focuses on how the young person's special educational needs may affect their learning and transition to adulthood.

Assessment should take place over a period of time, and is designed to result in a **Personal Action Plan**, which spells out how barriers to successful transition can be overcome.

Assessing a young person with MSI requires considerable specialist expertise. The PA will not be an appropriate person to complete the assessment directly. They will need to liaise with specialists in MSI, either from statutory services or from voluntary organisations.

College places

- College places are funded through your local authority, or in exceptional cases, the YPLA may commission provision directly.
- The LA also funds residential places at specialist colleges, when it is convinced of the necessity to do so.

Specialist colleges are usually residential and may be some distance from the young person's home. Many, but not all, belong to NATSPEC (see Resources section). Your son or daughter's Connexions PA will be able to explain how to request funding for a specialist college place. Such a place will only be funded if it is thought to be the most appropriate way to meet a young person's needs.

The **Disability Discrimination Act** requires colleges and universities to make **reasonable adjustments** to meet the needs of students with disabilities. These adjustments may include, for example,

- changing teaching arrangements,
- training staff and/or
- providing communication and support services.

The college can take factors such as cost and the maintenance of standards into account when deciding whether an adjustment is reasonable. Skill (the National Bureau for Students with Disabilities – see Resources section) can offer further help, as can organisations such as the RNID and RNIB.

Things to ask your child's PA:

- **What are the local options for post-16 education?**
- **What school provision is available post-16 in your area?**
- **What experience and expertise do local colleges have in complex needs and MSI? What relevant courses do they offer?**
- **What specialist college placements might be available, and what do they offer?**
- **Who will be involved with your child's Section 140 assessment?**
- **What training and experience do these people have regarding MSI?**

Health services

The health services for children with disabilities work differently to those for adults. Children with MSI are usually cared for by a local child development team, and may also be linked to hospital consultants with particular specialisms. Therapy needs may be specified in the child's Statement, either as educational or non-educational needs – speech and language therapy, in particular, is usually classed as an educational need. LAs are legally bound to provide therapy specified as educational provision.

Young people with MSI will move to adult health services at age eighteen. **Adult services** are usually provided through a local **community team supporting adults with learning disabilities**. Access to **therapies and other specialised support** does not automatically continue when a child reaches adulthood.

The health professionals involved with your son or daughter should provide written advice for the Transition Plan and attend the Year 9 transition planning meeting. They should discuss **transfer to adult health services**, including referrals to specialist services, with you, your son or daughter and your child's GP. Your son or daughter's records may also need to be transferred.

In their last year at school, your son or daughter will have a **Leaving School Health Check** and a **Health Action Plan** should be drawn up. Health Action Plans are individual plans for adults with learning disabilities; they state any health needs,

and detail how these will be met. Young people at transition are a priority group to be given Health Action Plans.

The **Disability Discrimination Act** applies to the NHS as to other providers of goods or services. People with disabilities should not be treated less favourably than those without – so, for example, a hospital should try to provide a BSL/English/other interpreter for a medical appointment if needed.

Things to ask your child's GP (or PA):

- **Who will co-ordinate your son or daughter's health services in adulthood?**
- **How will transfer to adult health services be arranged? Ask about each service your child receives.**
- **How will continuity of care be ensured regarding speech and language therapy, physiotherapy or other specialised services your child receives?**

Benefits

Benefits entitlements change at the age of sixteen. Young people can receive benefits in their own name at this age. They may be entitled to

- Incapacity Benefit (if unable to work),
- Disabled Person's Tax Credit (if working) and/or
- Income Support.

Claims for **Disability Living Allowance** may need to be renewed.

Young people aged sixteen or over can receive direct payments (in place of care services from Social Services) in their own name. They need not do so: care may be provided directly by Social Services, or direct payments may be made to the young person's parents. An individual may have different elements of their care funded through each of these channels.

Further information on benefits is available from the Disability Alliance (see Resources section).

Things to ask your child's social worker (or PA):

- **What benefits will your child be entitled to at age sixteen? How should these be claimed?**

Housing

Your son or daughter may continue (or return) to live at home, or move elsewhere. Transition planning should include future living options and any support or training needed to make them work. Housing options will also be addressed as part of the Community Care assessment by Social Services. MSI creates a wide range of needs, so that some young people will live independently, whilst others need full support.

Young people can join the local **housing register** at the age of seventeen. The housing department will also tell you about local **housing associations** which may be able to help.

If your son or daughter decides to live at home and you are happy with that choice, the support needed should be identified as early as possible. This may include

- support from social care workers,
- day services,
- respite care,
- adaptations to the house or flat,
- equipment,
- ongoing help and advice from specialists such as occupational therapists and rehabilitation workers.

Residential care may be in

- supported single accommodation,
- a small group home,
- a larger residence.

It may be provided near your home, or some distance away if the provision specialises in MSI. The level of support provided will depend on need, and there will be an emphasis on being part of the local community.

Things to ask your child's social worker (or PA):

- **What are the local options for housing for young people who are multi-sensory-impaired?**
- **What specialist residential provision might meet your child's needs?**

Employment

Better employment opportunities for adults with learning and other disabilities is a government goal. It is fair to say, however, that at present access to employment is lagging well behind access to further education.

Most young people with MSI will need considerable support in order to work. Paid employment will not be an appropriate goal for all. Connexions and the **Careers Service** can advise about potential jobs, although they are likely to need to liaise with specialists in MSI

Making a transition plan

(probably from Sense or another voluntary organisation). **Disability Employment Advisors (DEAs)** can be contacted at Jobcentre Plus.

Young people with Usher syndrome may face particular difficulties in choosing a career because of their changing visual needs. They may also find it hard to look ahead to a time when their vision will be more restricted, and may be unable to build this into their planning. It may be helpful for them to talk to an adult with the same type of Usher syndrome (see Resources section). Parents may also find such contact helpful.

The **Disability Discrimination Act** applies to employers with 15 or more staff. They must not treat employees with disabilities differently to other employees, and must make reasonable adjustments for those with disabilities – these might include changes to working practices or the environment. What is ‘reasonable’ will vary between employers – for example, it might be more reasonable for a large firm to spend more money than a small one on adapting premises.

Things to ask your child’s PA:

- **What employment options might be open to your child locally?**

Making a transition plan

Transition planning begins in Year 9, and continues until they are at least nineteen – the Transition Timeline on page 27 sets out what

happens when. The first formal meeting about transition is held in Year 9, usually at the Annual Review meeting.

Before the Transition Planning meeting

One member of school staff will have responsibility for arranging the Transition Planning meeting. They will know which **professionals are attending**, and why each one will be there. You should be told this before the meeting. Those attending are likely to include

- the Connexions PA,
- staff from your son or daughter’s school,
- an LA representative,
- professionals from Health and Social Services,
- any others involved in helping your son or daughter.

Some may send written reports rather than attending in person.

You may want to act before the meeting:

- If there are particular professionals whom you think should attend, tell the school well before the meeting (several months ahead), or they may not be available.
- You can take someone with you to support you at the meeting if you wish.
- You may want to ask if you can meet key professionals before the meeting date, particularly if they don’t know your son or daughter well.

- Ask what topics will be covered at the meeting. If there are other topics which you think need discussion (check through the list in the section What should transition planning cover?), ask for them to be added to the agenda.
- Be as clear as possible about what you want for your family. If your son or daughter won't be able to express their views during the meeting, or take decisions quickly, then it is even more important to think through the issues beforehand and to know your child's views.

The school should **help your son or daughter to prepare** for the Transition Planning meeting. This may involve any of the following:

- developing a transition passport or profile;
- discussing what the meeting is about and what will happen;
- offering the chance for your child to take a friend or advocate with them;
- helping your son or daughter prepare anything they want to say, perhaps using role play.

If your son or daughter is going to attend the meeting, their needs must be taken into account beforehand. A set of Guidelines for Planning Meetings is given towards the end of the booklet, in case professionals are unsure how best to meet needs.

At the meeting

Your son or daughter has a right to attend the Planning meeting, but they do not have to do so – for example, if they would find the meeting very stressful or distressing. A third option is for the young person to attend part of the meeting, usually the beginning. This may give them the chance to meet the professionals attending and to express their views. If they do not attend, then it is vital that their views are presented, not assumed.

- If your son or daughter does attend the meeting, they should receive all the support they need to do so. This should not come from you – you need to be free to take part in the discussion.
- Make sure that you are comfortable in the meeting room, that you can see and hear well and that you know who all the other people at the meeting are. If you forget this, ask.
- If something isn't clear, ask for it to be explained, and if you disagree with what is said, say so.
- If you feel that your son or daughter's wishes have been misinterpreted, say so – similarly, speak up if you feel that the options offered don't meet their needs.
- Always remember that you know your son or daughter better than anyone else.
- Take notes if you wish to – having a record can help afterwards.

- In order to make sure that you have time to give your views and that your child's views are expressed, either in person, through video or in any other way, let the Chairperson know in advance and then you will be confident there will be time for you to play an active part.

Transition Planning meetings are usually part of the Annual Review meetings. It is important to check that your child's Statement is still accurate, especially

- the description of needs (Section 2),
- the provision required to meet needs (Section 3).

There may be changes needed to support a curriculum that is more directed towards life after school. The Statement will be passed on to your child's post-school provision, so it needs to be accurate.

After the meeting

Don't feel that you have to take decisions straight away. You are entitled to ask for

- more information,
- more explanations,
- more time to think.

Your son or daughter will also need time to think about what has happened at the meeting. If they haven't attended it, or only attended part of it, they must be given the chance to respond to what has been said in their absence.

In most schools, the headteacher is responsible for drawing up each pupil's **Transition Plan**, although they may delegate this to the Connexions PA. In non-maintained special schools, the LA is responsible for the Transition Plan, but will probably ask the headteacher to arrange it.

You will be given a copy of your son or daughter's Transition Plan, which will be updated at least yearly. (If you are not given a copy, ask for one). Your son or daughter should also be given an accessible copy of the Plan or its main points if appropriate.

The Transition Plan should

- include your son or daughter's strengths, and how these can be developed, as well as areas of need;
- cover the actions needed to prepare the young person for adulthood, including contacts with external agencies and skills or concepts to be taught in school;
- set clear targets, and specify who will take what action when. Your son or daughter's Connexions PA is responsible for making sure that it is carried out;
- spell out what contact the PA will have with you and/or your son or daughter.

If you are not happy with the Plan, contact the Connexions PA and/or the headteacher in the first instance.

Putting plans into action

It is generally agreed that services for people with complex disabilities should be well-coordinated. In practice, however, different agencies have different criteria and structures for providing services. This means that there are a number of **different assessments and plans** for each individual. Young people with MSI are hard to assess accurately, and assessors need specific skills and expertise. This may need to be explained to several agencies in turn – a job which belongs to the Connexions PA, not to the young person's parents.

Plans are only useful if they result in action. Your son or daughter's Transition Plan is likely to include opportunities to try out possible post-school activities. **Visits or trial placements** may indicate new factors to take into account. The background noise levels in a workshop, for example, may prove to be too high, and activities taking place in quieter environments may need to be chosen instead.

Your son or daughter's transition will be discussed at each Annual Review following Year 9, and their **Transition Plan will be updated**. The cycle of planning, action and getting more information should be repeated each time.

Final decisions on post-school or post-college provision should not be taken at the last minute. Leaving a familiar setting for a new one is a hugely demanding experience for anyone, and especially for someone with MSI. Repeated visits and a gradual transition allow for emotional as well as mental and physical adjustment.

Information about the young person needs to be passed on to staff in the new setting, particularly if there are difficulties with communication. Profiles or passports can be very helpful here, but are not enough in themselves. Staff in the new setting need time to observe the young person in different situations, including interaction with people they already know well. Staff also need time for discussion with those who have previously worked with the young person.

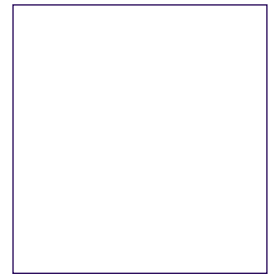
Moving from school to college is not the end of transition for any young person, but those without disabilities are likely to become increasingly independent and to need less structured support as they get older. People with MSI may continue to need considerable help with daily living and with making decisions, and **transition support may well need to continue** into their twenties. If this is the case, the Connexions Service is responsible for arranging appropriate support even if it does not provide it directly. Your son or daughter is entitled to such support, if they need it, until they are 25.

Transition timeline

age 13 (Year 8)	Connexions Service first involved – Connexions PA meets the young person at school.
age 14 (Year 9)	<p>Connexions PA continues to work with the young person, identifying where support is needed.</p> <p>School contacts Social Services to check whether the young person will be entitled to adult services at 18+.</p> <p>Transition Planning meeting held, usually together with Annual Review of Statement of SEN. Following this meeting, the Transition Plan is drawn up and copied to all those involved.</p>
age 15 (Year 10)	<p>Actions agreed in the Transition Plan should happen.</p> <p>Plan reviewed(probably at Annual Review meeting).</p> <p>Decide whether the young person will leave school at 16 or continue until 19.</p>
age 16 (Year 11)	<p>The young person may stay on at their current school, or leave for another school, college, employment training scheme or job. The Connexions PA may change if the young person moves from their current school, but Connexions involvement continues.</p> <p>The Transition Planning review should include representatives from the funding body and Employment Service.</p> <p>If the young person stays on at school, their Statement of SEN is maintained as previously until age 19.</p> <p>If the young person leaves school then LA involvement, including the Statement of SEN, ends. In this case, the Transition Plan ends and is replaced by a Personal Action Plan (coordinated by the Connexions PA).</p> <p>If the young person moves on to FE, training or employment, they should have an assessment of education and training needs (managed by Connexions PA) and a Leaving School Health Check.</p> <p>Health Action Plan is drawn up by health professionals – this should include services needed such as speech or physiotherapy.</p>

<p>age 16 (Year 10) (cont)</p>	<p>Social services will contact the young person regarding an assessment of needs – the Community Care assessment, leading to a Care Plan. Carers can ask for an assessment of their own needs.</p> <p>Benefits entitlements change at age 16. The young person can also receive direct payments (to pay for care services) in their own name.</p>
<p>age 17</p>	<p>Transition Plan or Personal Action Plan reviewed – meetings coordinated by Connexions PA if young person has left school.</p> <p>Community Care assessment should be carried out in time for services to be provided from age 18.</p>
<p>age 18</p>	<p>The young person is legally an adult.</p> <p>The young person transfers to adult Health and Social Services. Their Health Action Plan should specify health needs including access to therapies. Their Care Plan should detail support services needed – there may be a charge for services.</p> <p>A Leaving School Health Check and an assessment of education and training needs (managed by the Connexions PA) are carried out now if they were not done previously.</p> <p>Transition Plan or Personal Action Plan reviewed.</p>
<p>age 19</p>	<p>The young person leaves school if they have not already done so. LA involvement ceases at 19.</p> <p>The young person moves on to college, training, work or day services. If they are already at college, they may leave for other provision.</p> <p>Their Transition Plan or Personal Action Plan is passed on to their new provision.</p> <p>Connexions involvement may continue up to the age of 25.</p>
<p>age 20-25</p>	<p>Transition planning continues if necessary. The sources and levels of support are agreed jointly by the LA Connexions Service and the funding body.</p> <p>By age 25 at the latest, the young person should be supported by adult services.</p>

My transition profile



How to talk to me

What I can see and hear

What I like to do, at school and at home

What I don't like to do

Things I can do by myself

Things I need help with (and what help I need)

People and places I like

Things I want to do in the future

People I want to keep in touch with

Resources

Sense www.sense.org.uk Information about deafblindness, MSI, Usher syndrome, the rights of people with MSI and options for young adults. tel: 0845 127 0060

On the website are two helpful factsheets:

Setting up a Trust for a disabled family member

This factsheet covers everything you need to know about setting up a trust for a disabled family member.

Sense guide to making a will

This factsheet tells you all you need to know about making a will, including why it's important, how to write a will and an explanation of jargon you may come across.

www.usherlife.co.uk Usher Life is a dedicated website for people who have Usher syndrome.

www.transitioninformationnetwork.org.uk The Transition Information Network is based at Council for Disabled Children and is a national project providing a forum for young disabled people and professionals to exchange information and join events and activities that promote good practice.

www.trans-active.org.uk Primarily about a project linking young people with and without severe learning difficulties to provide support during transition. Includes a section on 'transition planning' which clearly explains the process of transition. Good list of resources and links.

www.connexions-direct.com Gives basic information about the Connexions Service.

www.skill.org.uk/youth National Bureau for Students with Disabilities. Includes information booklets on wide range of topics and information service.

www.natspec.org.uk NATSPEC (association of national specialist colleges) – website has a directory of specialist colleges and some questions to ask when visiting FE provision.

Equality and Human Rights Commission helpline: 0845 604 6610

website: **www.equalityhumanrights.com**

Sense runs a **Young Sense** project

Email: members@sense.org.uk

Disability Alliance – advice on benefits and charges

www.disabilityalliance.org

www.communicationpassports.co.uk Personal passports – for general use, but the approach could easily be adapted specifically for transition.

www.carersuk.org Carers UK is the voluntary sector organisation working to support carers. It published an excellent guide to the carers assessment.

www.adviceguide.org.uk is a Citizens Advice Bureau site which has clear information about benefits.

Contact a Family **www.cafamily.org.uk** brings together families of children with rare and low incidence conditions, including many that have a combined, acquired or congenital vision and hearing loss.

Information for Connexions PA/ other professionals

This part of the booklet is designed primarily for use by PAs. It explains some specific difficulties faced by young people who are multi-sensory impaired, and suggests guidelines for good practice during transition.

What is MSI?

MSI stands for multi-sensory impairment. Most people with MSI have both impaired sight and impaired hearing – a condition also called deafblindness. The majority have further disabilities such as physical, medical and/or learning difficulties.

The term MSI may also be used when people have one sensory impairment (sight or hearing) and multiple disabilities. The common thread that links people with MSI is extreme difficulty in gaining and using information from sight and hearing.

Some people with MSI or deafblindness are very able, attending mainstream schools and following the same curriculum as their peers, at the same level. Others have profound and complex needs and are highly dependent. Most will have difficulties with

- accessing information about what is happening around them;
- communication and relationships with others;
- mobility.

Making transition successful

There are a number of barriers to successful transition for young people with MSI. Some of these are common to most young people with severe disabilities, but some are specific to MSI:

- MSI is a very rare disability, so most professionals know little about it
- many young people with MSI get very little information from the world around them, so find it hard to make informed decisions or to think about events beyond the immediate here-and-now
- many young people with MSI have limited formal communication
- many young people with MSI have complex needs and require services from many different agencies
- MSI creates very complex needs, so that specialist expertise is essential for accurate assessment and good service provision

The rest of this section suggests ways of overcoming these barriers and promoting successful transition.

Making choices about the future

Some young people with MSI can discuss ideas and plans using signs, symbols and/or speech. Young people with Usher syndrome, for example, will have fluent communication skills using speech or sign. Many others have greater

difficulty. For these young people, making choices about what to do and where to live in the future may seem impossible, but there are a number of approaches which can help.

Parents or carers will know the young person best, but will need information about the services available locally and nationally. This booklet includes a number of charts for parents or carers to complete. These may provide a basis for discussion of the young person's needs and future options. School staff will also have a wealth of information about the young person's abilities and preferences, and ideas about how they can communicate their own wishes about their future.

Beginning from likes and dislikes

This will not be a problem for the young people who have **good communication skills**. Facilitating their input will still require planning. Some young people with MSI have profound disabilities and **very limited communication**. For these children efforts must be made to ensure they have the chance to "have their say".

Also parents, professionals and friends need to **share their ideas** of what the young person likes and dislikes, and also of how they know that the young person likes or dislikes these things. This gives a basis for discussion of what the young person might like to do on leaving school, what they might not like to do (equally important) and how they can best express their views.

The ideas discussed can indicate **new activities for the young person to try** whilst still at school. Their responses to these activities will give further information about their preferences and wishes, and the whole cycle can be repeated, with a better understanding of the young person's views emerging each time.

Making informed choices

MSI affects people's ability to learn about the world around them, because the information they get from their surroundings is very limited. This makes it hard for people with MSI to compare one experience with another, and makes it almost impossible for them to learn incidentally. For these reasons, people with MSI often have huge **gaps in their knowledge**.

Most children, for example, become aware of a range of careers as they grow up. They know what their parents do; they see teachers, doctors, sales staff and others at work around them; they see people on TV doing various jobs. They pick up information from a range of sources without needing to try. Young people with MSI, however intelligent, are unlikely to do this. They will not already have a fund of knowledge about options for living, working, learning and socialising which just needs topping up with accurate information. They will need to be **given all the information about a topic**, in a way in which they can understand and remember, in order to make informed choices.

Some young people with MSI are able to learn a lot from **videos, books and discussion**. Most, however, will need to **get information directly**, by experiencing the different options available.

A single visit to each **college or home or club** under discussion will not be enough. Those of us with full sight and hearing often find that we remember little of a first visit to a new place, especially if new activities are included and we need to make momentous decisions about the experience. People with limited sight and hearing get very limited information about what is happening to them, and minor details of an experience may be their main memory. **Repeated visits are needed** for them to build a more informed picture. On these visits, they will need **support from someone whom they know and trust** – the aim is not for them to ‘cope’ with new people, but to build information about a setting. Talking over the experience afterwards, using photos, pictures, objects, video and/or audio-recording, will help the young person to think about their experiences.

Because transition planning is an evolving process, the early stages of planning may lead to the **arrangement of visits, taster courses or link placements**. These provide the young person with a basis for making informed choices at later stages of the planning process. They also begin the process of transition to the new setting that is eventually chosen.

Expressing choices

Most young people with MSI **communicate much better with people whom they know and trust**. It is vitally important that the young person talks about transition with such a person – whether through speech, sign, symbols, gestures or body language. Some young people with MSI may clearly communicate choices (a preference for a particular group home, for example) by their behaviour in different settings, although they may not put the preference into any form of words. **Everyone, whatever their communication**, can indicate whether they like or dislike an experience, and so **make a choice**.

Sometimes, young people with MSI may make choices that seem unrealistic. These deserve close attention, both because the young person has a right to be listened to and because they may be very informative. Young people with MSI often have a very limited world-view because of their restricted access to information. What sounds like an unrealistic choice may be the closest they can get to expressing a different, more realistic option.

Sometimes, a choice that seems unrealistic may not be so, if **appropriate aids and support are provided**.

Changing needs

Some young people with MSI have **changing needs** due to changing levels of health, vision and/or hearing. Adolescents with Usher syndrome, which can cause deafness from birth and gradually deteriorating vision, may find their poorer night vision restricting their social lives just as their peers get more freedom. Transition planning may be the first time that the young person has had to face and plan for the reality of changing abilities. If they are to stay at the centre of the planning process, the adults involved must **respect the limits of the young person's ability to face change**.

Young people with Usher syndrome may have career plans which seem unrealistic to adults around them. These need careful thought. Is the plan really unrealistic? Careers involving driving are, but others may not be. Very few people have careers for life these days; what about the possibility of changing track later?

Provision for young people with complex needs

Many young people with MSI have **complex multiple disabilities** and receive **services from a range of agencies**. They and their families often know individual doctors, therapists and other professionals very well. Their transition to adulthood puts huge demands on parents or carers, who need to get to know both the **different systems operating in adult services**, and new practitioners.

MSI is a very rare disability, and many doctors, social workers and therapists meet only one or two people with MSI during their whole careers. This means that they **may not understand the very complex needs** of many people with MSI – in particular, they may assume most of their difficulties are due to learning disability, rather than to the effects of sensory impairments. This causes huge **problems in accurately assessing needs**, and therefore in **providing appropriate services**.

Most parents of young people with MSI are very wary about assessments of need and decisions about service provision. Some have already experienced poor practice at the hands of professionals with little specialist knowledge of MSI. It is very important that **assessments are carried out by people with appropriate specialist knowledge and expertise**. This may entail **buying in assessments from specialist providers** such as Sense. This may need to be explained to several agencies in turn – a job which belongs to the PA, not to the young person's parents.

Young people who receive a range of services need them to be well-co-ordinated. In practice, however, different agencies have different criteria and structures for providing services. This means that there are a number of **different assessments and plans** for each individual.

These need to be co-ordinated, both to avoid repeated assessments wherever possible and to make sure that the final set of plans is comprehensive and appropriate.

Parents or carers will need comprehensive information about adult provision. A number of questions that they might ask of different

agencies are suggested in this booklet. These are listed together below:

agency	who to ask	questions that parents may ask
Connexions	PA	<p>Who is the person, responsible for coordinating the services they receive?</p> <p>Does this person understand the specific needs of people with MSI?</p>
Social Services	social worker or PA	<p>When will a Community Care assessment happen?</p> <p>Which professionals will carry out the Community Care assessment? Do they understand the specific needs of people with MSI?</p> <p>When can an assessment of family needs as a carer be arranged? (Under Section 7 deafblind guidance)</p> <p>When can they arrange an assessment in accordance with Social Care for Deafblind Children and Adults?</p> <p>Who will carry out this assessment? What training have they received in MSI ?</p>

agency	who to ask	questions that parents may ask
Education	PA	<p>What are the local options for post-16 education?</p> <p>What school provision is available post-16 in your area?</p> <p>What experience and expertise do local colleges have in complex needs and MSI? What relevant courses do they offer?</p> <p>What specialist college placements might be available, and what do they offer?</p> <p>Who will be involved with Section 140 assessment?</p> <p>What training and experience do these people have regarding MSI?</p>
Health services	GP or PA	<p>Who will co-ordinate health services in adulthood?</p> <p>How will transfer to adult health services be arranged?</p> <p>That means each service received at present.</p> <p>How will continuity of care be ensured regarding speech and language therapy, physiotherapy or other specialised services ?</p>
Benefits	social worker or PA	<p>What benefits will this young person be entitled to at age sixteen?</p> <p>How should these be claimed?</p>
Housing	social worker or PA	<p>What are the local options for housing for young people with MSI?</p> <p>What specialist residential provision might meet this young person's needs?</p>
Employment	PA	<p>What employment options might be open to this young person locally?</p>

Planning and delivering transition

Plans are only useful if they result in action. Most young people with MSI will need opportunities to try out possible post-school activities. **Visits or trial placements** may indicate new factors to take into account. The background noise levels in a workshop, for example, may prove to be too high, and activities taking place in quieter environments may need to be chosen instead. The cycle of planning, action and getting more information should be repeated each year

Final decisions on post-school or post-college provision should not be taken at the last minute. Leaving a familiar setting for a new one is a hugely demanding experience for anyone, and especially for someone with MSI. **Repeated visits and a gradual transition** allow for emotional as well as mental and physical adjustment.

Information about the young person needs

to be passed on to staff in the new setting, particularly if there are difficulties with communication. Profiles or passports can be very helpful here, but are not enough in themselves. Staff in the new setting need time to observe the young person in different situations, including interaction with people they already know well. Staff also need time for discussion with those who have previously worked with the young person.

Moving from school to college is not the end of transition for any young person, but those without disabilities are likely to become increasingly independent and to need less structured support as they get older. People with MSI may continue to need considerable help with daily living and with making decisions, and **transition support may well need to continue** into their twenties.

Transition planning meetings – making it work for everyone!

1. The young person and their parents should know before the meeting which professionals are attending and why each one will be there. They should also have copies of written reports.
2. They may wish to suggest other professionals whom they would like to attend the meeting. They need to be asked about this far enough ahead to give these professionals reasonable notice.
3. The young person and their parents should know in advance which topics will be covered at the meeting, and have the chance to suggest others which are important to them.
4. Young people with MSI will need help in preparing for the Transition Planning meeting, whether or not they are going to attend. Depending on their abilities, preparation might involve
 - developing a transition passport or profile;
 - discussing what the meeting is about and what will happen;
 - offering the chance for the young person to take a friend or advocate with them;
 - helping the young person prepare anything they want to say, perhaps using role play.
5. Some young people with MSI may want to attend the whole of the meeting. Others may find the experience very stressful or confusing and prefer not to attend. Still others may wish to attend part of the meeting, usually the beginning. This may give them the chance to meet the professionals attending and to express their views.
6. If the young person does not attend the meeting then it is vital that their views are presented, not assumed. Video recordings, showing the young person taking part in a range of activities, can be very helpful if some of those present do not know the student well. A transition profile or passport, or some other record of the young person's wishes, is better than a purely verbal report from someone else.
7. If the young person does attend the meeting, its location should be carefully chosen. Many people with MSI need a familiar environment if they are to concentrate on receiving other new information. The young person might be better served by a meeting in their classroom or another familiar setting than by an 'official' meeting room that they rarely enter.
8. The room also needs to be suitable for the needs of those attending. If BSL/English interpreters are used, for example, there must be enough space for the interpreter to work comfortably. People with hearing impairments need good acoustic conditions. The visual environment should suit the needs of those attending – for example, avoiding glare from shiny table-tops if necessary.

9. The young person should be seated where they feel comfortable and respected, and next to someone they trust – preferably not a parent, however, as parents need to be able to concentrate on the discussion.
10. Most people with MSI find communicating and following others' communication in a large group very tiring, whether or not they use an interpreter. They will need frequent breaks, and the chance to go back over anything missed or not understood.
11. Some young people with MSI will need the main points of what is said to be summarised and presented using signs or symbols. This may take time, especially if symbols are used, but preparation before the meeting can identify many of the words that are likely to be needed.
12. The young person and their parents may need time after the meeting to think through what has been said, and perhaps to ask for more information, before reaching any decisions.
13. As well as a copy of the full Transition Plan, the family should be given an accessible copy of the Plan or its main points for the young person if appropriate. The Transition Plan should:
 - include the young person's strengths, and how these can be developed, as well as areas of need;
 - cover the actions needed to prepare the young person for adulthood, including contacts with external agencies and skills or concepts to be taught in school;
 - set clear targets, and specify who will take what action when;
 - spell out what contact the PA will have with the young person and with their family.

Sense

101 Pentonville Road
London N1 9LG



Tel: 0845 127 0060



Fax: 0845 127 0061



Text: 0845 127 0062



Email: info@sense.org.uk



Website: www.sense.org.uk

Registered charity number: 289868 Company Limited by Guarantee

Registered in England and Wales. Company number:1825301

Patron: Her Royal Highness The Princess Royal

Produced 2009, updated 2010