



Preparing for adult life and transition

Information for families

England and Wales

Incorporating **The Lady Hoare Trust**

Introduction

Leaving school or disabled children's services and moving into adulthood can be a challenging time for young people and their parents. What kinds of choices exist and will they help the young person lead a fulfilling life? Many parents feel anxious at this time, predicting poor services or a possible lack of choice for their children. The support they may have enjoyed through local parents' groups or local children's services will be moving away.

This guide aims to bring together some of the main issues that parents and young people need to think about, with some useful contacts for more detailed advice on each. It's written for parents with children of 13 years of age and over, as 13 to 14 is the age when the transition process should begin.

Please note

Throughout the factsheet we use the term **Local Authority** or **LA** when referring to the part of the local authority that's responsible for education, which used to be known as the Local Education Authority (LEA). This is in response to the Department for Education (DfE) decision to use this wording. In your area it may be called 'Education and Learning' or 'Children's Services' now.

Note: The Code of Practice for Special Educational Needs still refers to Local Education Authority (LEA).

Contents

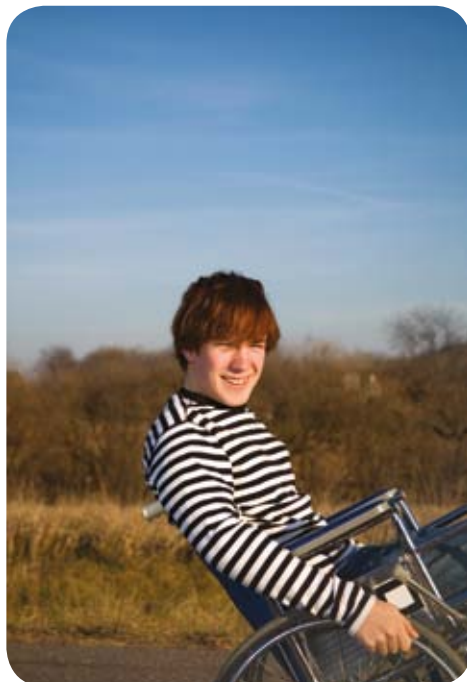
Starting to think about transition	3
The transition plan.....	4
Contributing to the plan	5
How parents can contribute	6
How the young person can contribute.....	6
After the transition plan review meeting	10
Checklist: the transition plan.....	10
Further or higher education	12
Employment	14
The Equality Act 2010.....	15
Help with care needs	16
Health, housing and leisure for young people.	22
Money post-16	24
Wills and trusts.....	25
Further reading and useful contacts .	25

Starting to think about transition

If your child has a statement of SEN

In school year 9 (the year in which young people turn 14 years of age), if your child has a statement of special educational needs (SEN), the head teacher will write to you to invite you to the forthcoming annual review. This review must include the drawing up of a transition plan. If your child has a statement but does not attend school, the local authority (LA) will arrange the meeting.

It is important to note that a statement of SEN can remain in force until the age of 19 as long as the young person is in a school. If a LA wants to cease the statement, for example if a young person



is going to a Further Education college, they must first carry out a Learning Difficulty Assessment to judge whether provision for that young person's needs can be met.

If your child doesn't have a statement of SEN

If your child has special educational needs but doesn't have a statement, they may still need additional support to plan their transition to adulthood.

The Careers Advice service (Careers Wales in Wales), previously known as Connexions, provides support for all young people of 13 to 19 years of age.

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**



Careers Advice services now differ across each LA so get in touch with them to see what support your services can offer for the transition process.

They have a responsibility (a legal 'duty' in Wales) under section 139a of the Learning and Skills Act 2000, to make sure all young people who have difficulty transferring to further education or training, have a learning difficulty assessment in their final year of school. This is a written report of the individual's education and training needs, and the provision required to meet these needs.

This plan, with the young person's permission, will be passed on to the new learning provider.

It's good practice for young people with special educational needs who are on School Action or School Action Plus to have a transition plan, but this is not compulsory.

The transition plan

What should a transition plan cover?

The SEN codes of practice covering England and Wales make it clear that transition planning should address questions concerning the young person, their family, the school and the

'The Transition Plan should draw together information from a range of individuals within and beyond school in order to plan coherently for the young person's transition to adult life. Transition Plans, when they're first drawn up in year 9, are not simply about post-school arrangements, they should plan for ongoing school provision, under the statement of SEN as overseen by the LEA.'

(Special Educational Needs Code of Practice, Para 9:51)

professionals supporting them. Questions should include:

- what are the young person's hopes and aspirations for the future and how can these be met?
- will parents experience new care needs and require practical help?
- how can the curriculum help young people play their role in the community?
- does the young person have any special health or welfare needs that will require planning and support from health and social services, now or in the future?

A transition plan should build on the conclusions reached and targets set at previous annual reviews of a child's statement of SEN.

When should a transition plan be drawn up?

The Education Act 1996 states that the LA must include a transition plan in the first review after 14 years of age. The process starts with the annual review meeting in Year 9 where a transition plan is drawn up. Parents are invited on equal terms with professional staff.

Contributing to the plan

Who may attend the transition plan review meeting?

The Year 9 review follows the same procedure as previous annual reviews but with some additions. All local services can be invited to the meeting, but some services must be invited and some have obligations to attend:

Named professionals involved

All schools have a duty under the Education Act 1996 to have SEN policies which take account of transition plan arrangements. The policies must name the relevant local professionals – for example local health and social services should both have designated officers to take responsibility for statutory assessments.

- social services must be invited to ensure that the young person's care needs are fully assessed
- health professionals involved in the care of the young person should provide advice towards the transition plan and where possible attend the meeting
- LAs have a statutory duty to provide a careers advice service to your child. This used to be called the Connexions Service in England or Careers Wales. If a representative for careers advice is not able to attend, the young person and you should be offered a careers guidance interview before the review and notes from this meeting should be made available at the review meeting
- a relevant teacher and a representative from the LA must be invited
- parents and carers must be invited your child's views must be sought and recorded
- the head teacher can invite anyone else they consider appropriate.

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Transition planning should address questions concerning the young person, their family, the school and the professionals supporting them.

How parents can contribute

You have a vital role in collecting relevant information because you know all the important people and activities in your child's life. You also know what you may be able to do to help in the future and may be aware of some of the choices available.

Make a checklist

It is helpful to make a checklist of everyone who has been working with your child and who has information that will be important in the review meeting. Not everyone who is invited will be able to come to the meeting so positive written information from professionals who know your child well is vital for devising the transition plan.

Your views

It is also helpful to think about your input as a parent and carer, for example:

- how can you contribute to your child's personal and social development?
- will your child's care needs change as they get older?
- how do you see your child's future?

Your child's interests and achievements

It is helpful to start keeping a record of your child's interests and achievements, including leisure ones, in case this comes in handy when taking up a particular course later on. Don't forget to include any records of achievement from school.

Bringing additional evidence to the meeting

Parents have the right to present additional and independent evidence at the review meeting. Get copies of reports in advance of the meeting.

Getting copies of reports in advance of the meeting

The code of practice states that for all annual reviews, including the one where the transition plan is drawn up, all participants, including parents should have a copy of all the written reports at least two weeks before the meeting.

How the young person can contribute

Young person's advocate

Young people with communication difficulties will need to be represented by a close family member or support worker who can advocate on their behalf.

Some young people find it helpful to talk to someone they already know and trust. Others find it more helpful to work



with local advocacy or support schemes which can help them identify what they would like to do. Social services or a local disability information service will know about local advocacy schemes. It is important that young people have a chance to share their concerns and ideas - both inside and outside the family.

'The views of young people themselves should be sought and recorded in any assessment, reassessment or review from year 9 onwards. Personal assistants, student counsellors, advocates or advisors, teachers and other school staff, social workers or peer support may be needed to support the young person in the transition process.'

(Special Educational Needs Code of Practice, Para 9:55)

A young person's needs

They might need to discuss personal concerns such as:

- making friends and having a social life
- sexual relationships
- the financial implications of leaving home
- getting enough help at college or university
- ageing parents
- personal care.

Person centred planning

In England, Valuing People is the government's plan for making the lives of people with learning disabilities and their families better. In Wales there

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**



Case study – transition in Westminster

A youth arts organisation specialising in dance, drama, music and video, works with disabled young people to create a record of things they like, what their aspirations are, their favourite lessons and so on.

This is usually in the form of a short video, which is then shown at the Transition Review meeting. Young people sometimes choose to be present at the meeting when the video is being shown and sometimes choose not to be.

Each young person nominates the person they would like to work on a plan with them; this can range from one person to a group of people. The young person is always at the centre

and throughout the process keeps their plan with them.

There are a number of areas that need to be covered, discussed and worked through but the young person chooses which part of the plan they would like to work on first.

All plans look different – for example some young people choose to have their plans typed and might look quite 'official' whilst others prefer to use videos. One young person currently has a box of information including a DVD of important people and friends, a photo album and a laptop where other information is held.

With thanks to the Council for Disabled Children for this case study

is a similar policy known as Fulfilling the Promises. The policies state that as young people grow up, getting the support they and their family need should be straightforward. Young disabled people should be given opportunities to reach their full potential and fulfil their ambitions. To achieve this during transition there should be person centred planning. Person centred planning means doing things in a way which meets the needs of the individual, and taking their views into account when decisions are made. Person centred planning is about:

- listening to and learning about what people want from their lives

- helping people to think about what they want now and in the future
- family, friends, professionals and services working together with the young disabled person to make this happen.

A guide to person centred planning is available from

The British Institute of Learning Difficulties (BILD)

Campion House, Green Street,
Kidderminster, Worcestershire DY10 1JL
Tel: 01562 723 010
www.bild.org.uk/05faqs_5.htm

Tips for talking about transition

Parents

- try not to assume what your child wants from the future – ask them what's important to them
- get information about all the options in advance of meetings, for example education and support for living independently
- before meetings, encourage your child to make a list of the items they would like to discuss
- ask your child how they want you to support them in meetings
- encourage your child to do the talking if they feel able to
- in meetings, prompt rather than take over. If you think your child's questions haven't been answered, ask them if they would like to go back to any issue to discuss more.



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Web: **www.cafamily.org.uk**

After the transition plan review meeting

Responsibility for the plan

The head teacher, in consultation with the must ensure that the transition plan is drawn up. The LA must ensure that all the services identified as necessary in the transition plan are available for the young person as they go through the transition period until they leave school.

Reviewing and updating the plan

The plan should be reviewed at all subsequent annual reviews until then.

Getting a copy of the plan

Once the transition plan has been drawn up, this must be circulated to you, the head teacher, social services, relevant health contacts and any other relevant professionals and carers.



Checklist: the transition plan

Year 9 – academic year of 14th birthday

- the head teacher writes to invite you to the 14+ Transition Review, to discuss the transition plan
- the head teacher must invite social services to the review
- social services should ensure a social worker attends the review meeting when a young person is subject to a care order, accommodated by the local authority or is a 'child in need'. A disabled child will usually count as a 'child in need'
- a representative from a careers service must be invited to and attend the Year 9 review. In Wales, a representative of Careers Wales must be invited and must make every effort to attend
- the LA should apply for funding from the Skills Funding Agency or the Young People's Learning Agency in England or the Welsh Government, if relevant
- health authorities and trusts should be made aware of the review and can attend and contribute.

Year 10 – academic year of 15th birthday

- the school is still responsible for arranging the annual review meeting
- parents are notified of the 15+ Review. This is an opportunity to think if you and your child want any changes to the plan
- you and your child can approach your careers adviser or representative of Careers Wales for further guidance
- you may want to make visits to local colleges or other post-16 services.

Year 11 – academic year of 16th birthday

- is the transition plan still relevant?
- when your child reaches 16 years of age, social services children's team will liaise with the adult care manager about any planning meetings that might be needed
- a representative from a careers service should attend the review in Year 11 to ensure the transition plan is updated appropriately. For young people leaving school, there is also a duty under the Learning and Skills Act 2008 to ensure that a Learning and Skills plan document is completed identifying any ongoing education. This should take account

of what's in the annual review of the Statement of SEN and the transition plan

- the LA should apply for funding from the Skills Funding Agency or the Young People's Learning Agency in England or the Welsh Government, if relevant
- there could be major changes to the young person's benefits. More information about this is available in the Contact a Family guide 'Money when your child reaches 16 years of age.'

Year 12 – academic year of 17th birthday

- 17+ Annual Review: is the transition plan in place and still relevant? What changes need to be made?
- at 18 years of age, transfer to an adult care team takes place. This process may take place when your child is 16 or sometimes at 19 years of age
- finally, on leaving full-time education (school or college), the young person is covered by the Disabled Persons Act (see page 15)
- a careers service/Careers Wales can provide on-going support to young people with special educational needs until they are 25.

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Further or higher education

A successful transition plan will have made sure that the young person has a clear understanding of what educational opportunities exist after leaving school. Where they continue their education will depend on the type of course the young person wants to take.

It is important for potential students to visit the school or college they are thinking of joining so they can meet staff and other students and discuss their support needs.

Education options post-16

There are many different options for young people who want to continue their education after the age of 16:

- **School sixth form**

Some schools (both mainstream and special schools) accept students beyond 16 years of age. If your child's current school does not offer the courses they want, they can choose to attend another school.

- **Further education colleges**

Further education and sixth form colleges usually offer a wide range of courses, including academic courses, work related courses (vocational) and general courses to prepare for adult life.

- **Specialist colleges**

Some young people may want to attend a specialist college to continue their education. They offer a range of education options and many are residential.

- **Higher education institutions**

After attending a school sixth form or further education college, some young people may want to continue their education at a university (some further education colleges offer higher education courses). To enter higher education, you have to follow a progression route gaining certain qualifications.

- **Work-based learning**

Work-based learning gives young people the opportunity to learn how to do a job, gain skills, work towards qualifications and maybe get paid whilst learning. There are different schemes available including:

- Apprenticeships
- Entry to Employment (E2E)
- New Deal
- 14–19 Diploma.

It is important to note that a statement of SEN can remain in force until the age of 19 as long as the young person is in a school. If a LA wants to cease the statement, for example if a young person is going to a Further Education college, they must first carry out a Learning Difficulty Assessment to judge whether provision for that young person's needs can be met.



For further information about post-16 education, contact:

Disability Rights UK

12 City Forum, 250 City Road, London EC1V 8AF

Helpline: 0800 328 5050

www.disabilityalliance.org

www.skill.org.uk/youth

Have taken on some of the services that Skill: National Bureau for students with disabilities previously delivered. This includes a young people's website and a helpline.

LearnDirect

PO BOX 900, Leicester LE1 6XJ

Tel: 0800 101 901

Textphone: 08000 568 865

www.learndirect.co.uk

Provides general advice about courses anywhere in the UK.

Education grants programme and advice- Family Action

501–505 Kingsland Road, London E8 4AU

Tel: 020 7241 7459 (2pm to 4pm on Tuesday, Wednesday and Thursday only)

www.family-action.org.uk/

EGAS is run by Family Action and offers guidance and advice on funding for those studying in post-16 education in the UK. It provides information on sources of funding including loans, grants, benefits, access funds, hardship funds, bursaries and charitable trusts.

Skills Funding Agency

Cheylesmore House, Quinton Road, Coventry CV1 2WT

“The opportunity to go away from home at 19 years old on a three year residential specialist college was a positive stepping stone to moving on for both my daughter and me as a mum”

Julia

Tel: 0845 377 5000

Helpline: 0800 100 900

<http://skillsfundingagency.bis.gov.uk>

Provides a Next Step helpline service to assist adult learners with information, careers and skills advice. They do not fund individual learners but do fund companies and colleges.

Careers information and advice for young people – DirectGov

Tel: 0800 100 900

Textphone: 08000 968 336

www.direct.gov.uk

Provides advice for young people on their future through text, phone, email or webchat.

Freephone helpline: **0808 808 3555**

Web: **www.cafamily.org.uk**

The Welsh Government

Cathays Park, Cardiff, CF10 3NQ

Tel: 0845 010 3300

<http://new.wales.gov.uk>

Has responsibility for funding, planning and promoting all post-16 education and training in Wales except higher education. This includes further education, private and voluntary sector training, adult continuing education and sixth forms.

Transport and post 16 education

Local Authorities must publish an annual transport policy which sets out what they will provide to students aged 16–19 to help them to get to a college of further education. The policy must include provision for students with additional needs. It should set out what kind of travel assistance is available, who is eligible for this assistance and how this will be assessed. There is no automatic right to a particular form of transport, but LAs should always consider the student's individual needs before making a decision.

Financial help with transport, or further advice on other sources of funding should be available from the college learning support department. Transport can be funded by Social Services if they have the resources to do so.



Employment

Some young people may want to move into work when they finish school. There are a number of agencies and people who can help.

Jobcentre Plus

Tel: 0845 6060 234

Textphone: 0845 6055 255

<http://tinyurl.com/38susz9>

Provide a range of services. A Disability Employment Adviser (DEA) can provide extra employment support to disabled people. They can help with an employment assessment to produce an action plan for getting a job and provide further details about help available. For more information contact your local Jobcentre Plus or visit their website

Careers Wales

Tel: 0800 100 900 (via LearnDirect)

www.careerswales.com

Provides careers information, advice and guidance to help young people and adults make informed decisions about learning and career options in Wales.

Careers Information and Advice for Young People

Tel: 0800 100 900

Textphone: 08000 968 336

www2.cxdirect.com/home.htm

Service specifically for young people aged 13–19 to receive careers advice. They offer a texting service and a call back service as well.

Adult day centres

Some individuals may need the support and training offered by day centres. These are usually run by social services departments, but may be run by voluntary organisations. These centres offer ongoing training in areas like independent living and work skills. If a placement is offered it could be short or long-term depending on a person's needs. Most users are 19 years of age or over. Referral for a placement is through a social worker. However, there are not many adult day centres left. It's more likely that there is a scheme with community based activities.

Supported employment

This focuses on placing disabled people in employment and training which leads to long-term employment. For more information contact:

British Association for Supported Employment (BASE)

Unit 4, 200 Bury Road, Tottington,
Lancashire BL8 3DX
Tel: 01204 880733
<http://base-uk.org/>

Disability symbol (two ticks)

Awarded by JobCentre Plus to companies that have made certain positive commitments towards employing disabled people. The symbol may be used on job adverts and application forms.

Work-based learning

See section 'Further or higher education'.

The Equality Act 2010

In 2010 the Disability Discrimination Act 1995 was replaced by a new piece of legislation called The Equality Act 2010.

If your child has a disability, they may be covered by the The Equality Act 2010. The Equality Act makes it unlawful for a disabled person to be discriminated against in areas like employment, accessing goods, facilities and services, and in schools and other places providing education.

Under the Equality Act disability discrimination occurs when:

- a disabled person is treated less favourably than someone else and the treatment is related to their disability and cannot be justified
- there is a failure to make a reasonable adjustment for a disabled person.

There are also measures covering victimisation and harassment.

Defining disability

The definition of disability used in the Act is 'a physical or mental impairment, which has a substantial and long-term adverse affect on a person's ability to perform normal day-to-day activities'. Your child does not need to have a statement to meet this definition.

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

Disability discrimination at school

More information on how this applies in schools can be found in our guides, 'Special Educational Needs – England' and 'Special Educational Needs – Wales'.

Rights in post-16 education

In regard to post-16 education the Act applies to:

- further and higher education institutions
- LA's securing further education, including adult and community education
- schools providing further education for adults
- LA's providing statutory youth services.

and covers:

- admissions, including when enquiring about and applying for a course
- teaching and learning and other student services provided mainly for students, including work placement, outings

and trips, leisure facilities, student accommodation

- exclusions from a course or institution.

With regard to employment, the Act applies to employers and covers:

- the recruitment process
- the terms and condition of employment
- chances of promotion, transfer, training and benefits
- unfair treatment compared to other workers
- harassment and victimisation.

More detailed information about the Act is available from:

Equality and Human Rights

Commission Helpline – England

Freepost RRLG-GHUX-CTR, Arndale House, Arndale Centre, Manchester, M4 3EQ

Tel: 0845 604 6610

Textphone: 0845 604 6620

Wales

Freepost RRLR-UEYB-UYZL, 3rd Floor, 3 Callaghan Square, Cardiff, CF10 8810

Tel: 0845 604 8810

Textphone: 0845 604 8820



Help with care needs

Up to 18 years of age, the needs of your son or daughter are assessed under the Children Act. From the age of 18 there is a transfer to adult services under the NHS and Community Care Act 1990. This Act incorporates other legislation including the Chronically Sick and Disabled Persons Act 1970.

Finding out what is available locally

Each local authority is now required to publish a community care plan which must outline what services they intend to provide to those who fall within the scope of the Act. This Act also requires service providers to consult with service users and their carers. Contact your local Family Information Service (FIS), social services department or a local disability organisation for details.

Family Information Services

<http://tinyurl.com/3rh4ltq>

The Daycare Trust website allows you to search for your local family information service which will be connected to your LA. The family information service will be able to provide you with information on local services to help you support your children. This is available to parents of disabled children up until your child's 25th birthday.

Getting an assessment

A vital part of community care legislation is the right of those who need support to have a full assessment of their needs. This assessment should look at a person's needs as a whole and not take each one separately. This assessment or care plan should be linked up with the work already undertaken in producing the transition plan. Assessments for carers and the cared for person are the responsibility of your local social services department.

For further information on legislation for carers and how it affects young adults with disabilities and carers call the Contact a Family helpline or see our



guide 'Disabled children's services in England and Wales'

Carers UK also produce a useful range of publications for carers:

Carers UK

20 Great Dover Street, London SE1 4LX
Tel. 020 7378 4999
Carersline: 0808 808 7777
www.carersuk.org

Carers Wales

River House, Ynys Bridge Court, Cardiff
CF15 9SS
Tel: 02920 811 370
Carersline: 0808 808 7777
www.carersuk.org

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

Disabled Persons Act assessment

Under the Disabled Persons Act 1986 the following procedure for assessment should take place. This process should be parallel to and linked with the transition plan described previously.

- the education department of the LA must seek information from social services as to whether the young person with a statement is disabled and establish if they will need services from social services when they leave school
- eight months before a young person with a disability is due to leave full-time education, the education department is required to notify social services in writing
- once social services have been notified they are obliged to co-ordinate a multi-agency assessment of the young person which must be completed no later than three months before the person's school or college leaving date
- the carers of the young person, as well as the young person, should be encouraged to take a full and active part in this process. This can include

the right to refuse an assessment or a particular service if this is their wish. Such a refusal would not bar a person from receiving help in the future

- the final report from this assessment should be discussed with the young person. After any agreed amendments have been made the report should be circulated to all relevant professionals, family members and any other carers
- after the assessment and report have been produced the social worker should organise a review meeting where the information in the report should be discussed and relevant plans for the young person laid out. A member of the adult care team should be present at this meeting.

Carers' assessments

As a parent/carer of a young person with disabilities you are also entitled to an assessment, known as a carer's assessment. This is done by social services and may be done alongside the young person's assessment or separately. The aim of the carer's assessment is to

Making decisions

The Mental Capacity Act came into force in 2007 and provides a statutory framework to empower and protect people who may lack capacity to make some decisions for themselves. One of the key principles is a presumption of capacity unless proved otherwise. The Act also establishes a general right for family members and other carers to be consulted about a person's best interests.

In some circumstances (for example, if there is a dispute about what is in the person's best interests) it will also be possible for a family member to apply to the new Court of Protection for the power to make decisions about the person's welfare, finances and certain aspects of their medical care. These sorts of powers are only likely to be granted if the Court of Protection is convinced that they are absolutely necessary. For further information about the Act and its implications contact the helpline.

look at the care you are providing for the young person and the type of help social services can provide to support you. As your child goes through transition their needs may change, and your role as a carer may change too. Ask your child's social worker or social services for more information.

What support services are available?

It would be misleading to say that there is a comprehensive support network of services available to individual young people and their carers once a person has left full time education. It is important, however, for the plans that are being made through the transition period to include not just services that do exist but also to say what other services should exist if the person is to be properly supported.

The Chronically Sick and Disabled Person Act sets out what kind of help should be provided. Under this Act, the duty to provide services is to the individual disabled child or adult and does not extend to other members of the family.

The services detailed are:

- practical assistance in the home, such as help with the personal care of your child, for example help with getting in and out of bed
- provision of equipment to satisfy a recreational need, like a TV, radio or computer
- travel and other assistance, like travel to and from a day centre
- home adaptations facilities like fitting handrails or hoists



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- holidays
- meals
- telephone equipment.

In the following sections we have signposted some of the core support services that should be considered.

Direct Payments

Local authorities can give payments, instead of services, to allow disabled people and carers to buy in the services they've been assessed as needing.

Direct Payments are seen to promote the independence of parents and their disabled children who would like to manage their own social care needs.

If a young person is under 16 years of age, Direct Payments will usually be made to the parent. When a child becomes 16, they can receive payments in their own right, to allow them to buy in the services they have been assessed as needing. In the past you couldn't insist on Direct Payments, but in England and Wales a request should only be refused in very limited circumstances now.

How much are Direct Payments?

The amount you receive should be enough to allow you to meet all the costs involved including tax and National Insurance as well as the fee for a police check (if you employ help directly). Social services will usually deduct an amount from the payments equivalent to what you would have been charged if they'd arranged the services. Alternatively, social services may make the payments in full and ask you to reimburse them any assessed charge. Any payments you receive must be used to pay for

services to meet the assessed needs. For more information see our guide 'Getting direct payments for your disabled child (England and Wales)' available free from our helpline.

Short breaks

Local authorities provide services for both disabled children and adults to give carers a break. Again, if it is anticipated that this care will be needed into adulthood then this must be included in the transition plan.

Your social worker should be contacted for details on short break options. The voluntary sector is now a major provider of short break services too. Your social services department should have further details.

As well as residential short breaks, there may be a local family based scheme or befrienders providing this help.

Vouchers

The Carers and Disabled Persons Act 2000 also allows local authorities in England to provide vouchers. This should enable carers and disabled children to receive vouchers for short breaks at the time of their choosing. But in both England and Wales, the scheme is discretionary so they haven't been widely taken up by local authorities. If you would like to know more about the scheme the helpline should be able to keep you up-to-date.

Case study - direct payments

Daniel, a young disabled person discusses how direct payments have helped him gain independence and take control of his life.

“Hi, my name is Daniel and my mum supports me with my direct payments. When we first applied for Direct Payments, I was only 15 years old. Now I am 18, I’m happy to get direct payments paid to me as that means I can be in control of my life, and do activities with people my own age. My mum is still allowed to support me but she is slowly handing over control to me: my money, my life!

We started off with Sally. She has been supporting me ever since I first got direct payments, but she is soon going to make a career change and won’t be available for so many hours in the future.

Then we recruited Kieren, who is the same age as me. He’s great because he takes me out to the cinema, gigs, parties, swimming, pubs, all over the place. The other day I took a girl to the cinema; it was my first date, and Kieren came along with us. He’s like a friend to me and I love having him over to support me.

Kieren has now finished his A-levels and will be looking for permanent work. I understand that the people around me will continually change, which is sometimes difficult for me because I get to like people and then they go, but I have to be mature about this.

About a week ago, I interviewed another support worker called Natasha who is also 18 years old. She is coming out with Kieren and me tonight so that she gets some idea about how to support me. My mum has said she will help train her up before leaving me on my own with her.

We’re also looking to recruit somebody to do occasional driving. Sometimes I’d like to go out in Aberystwyth and my mum doesn’t want to drive me there. I also have a lot of hospital appointments; it would be great to have someone else to drive me there, and maybe make a day out of it.

Direct payments have been great for me. For the first time in my life I’m spending time with people my own age, and I don’t have my mum hanging over me. She’s OK but who wants their mum tagging along with them when they go out!”

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

Independent Living Fund (ILF)

Equinox House, Island Business Quarter,
City Link, Nottingham NG2 4LA

Tel: 0845 601 8815

Text: 0845 601 8816

www.dwp.gov.uk/ilf

This is an independent discretionary trust fund. The ILF works in partnership with local authorities to organise joint care packages of services/direct payments. This enables disabled people with high care needs to buy in extra support. There are various conditions for applying, for example the disabled person must be aged at least 16. It is a discretionary fund which means that each person will be looked at individually.

To find out about eligibility, contact your social services department and ask for an assessment, saying that you want to apply for ILF. On application, a visiting social worker from the ILF will arrange a joint visit with a local authority social worker to discuss care needs and agree what is needed. The ILF's social worker will then make a written report with recommendations to the ILF.



Health, housing and leisure for young people

Health

GPs remain the first point of contact for primary health care services. However, some paediatricians will continue to see their patients into adulthood, particularly if there is a growth or development delay or rare disorder. This is not generally seen as good practice though and there should be a planned transition to an adult clinician.

Health service input into the transition plan

It is important that a health professional is involved in the drawing up of the transition plan, for example the person's GP or the school doctor or nurse.

The GP should be the first point of contact after leaving school if physiotherapy and/or speech therapy services are required. Any therapy required should have been identified in the transition plan so that all services are aware before an individual leaves school.

Access to health services

For access to occupational therapy a referral can be made by a GP, hospital or social worker. If a person is attending social services day provision then they should have access to health services there.

Access to equipment can be through the GP, social services, physiotherapist or occupational therapist. Call the Contact a Family helpline for a copy of our factsheet, 'Aids, Equipment and Adaptations'.

More information is also available from:
Disabled Living Foundation
380–384 Harrow Road, London W9 2HU
Tel: 0845 130 9177
Textphone: 0207 432 8009
www.dlf.org.uk

Sex and growing up

Advice on sexual health may also be available through the local GP or clinic. It is also worth contacting a local family planning service if one exists in your area. Voluntary organisations may also be able to help. Contact a Family produces 'Growing up, sex and relationships' packs for young disabled people, parents and teachers. Contact the helpline if you would like a copy.

Family Planning Association (FPA)

50 Featherstone Street London EC1Y 8QU
Tel. 0845 122 8600
www.fpa.org.uk

Produce 'Talking together about Growing Up' an illustrated workbook for parents of children with learning difficulties. Also produce 'Talking Together... about Sex and Relationships' a follow-up pack aimed at young people with learning difficulties aged 13 or above, plus resources for professionals.

Housing

Local authority housing departments are responsible for drawing up strategies that address the full range of housing needs in their area. This includes co-operation with the private and voluntary housing sectors. Housing authorities are legally obliged to work with social services departments in drawing up community care plans and promoting community

care through joint policies. In practice this should mean that they address the needs of young disabled people through supported housing, mainstream housing and through services like home adaptations and advice.

Living away from the family home

If it is appropriate for the young person to live away from home once they have left school, then it is very important that this has been included in the transition plan. There are several options that can be considered, including a placement in a residential home or an independent living scheme. This is available through the statutory, voluntary and private sectors.

Your first point of contact should be your social worker, although you can write to different voluntary and private organisations asking them to send you information. Your local authority housing department should also have details of specialist housing schemes and housing associations with accommodation in your area. It is very important to visit potential new housing and to look at all the options before any decisions are made.

Housing Options

Rodney Chambers, 40 Rodney Street,
Liverpool, L1 9AA
Tel: 0845 456 1497
www.housingoptions.org.uk

Housing Options is an independent advice and information service for people with learning disabilities.

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

Housing advice

Ring our helpline for details of local housing advice agencies.

Leisure

Your local authority should have information about leisure opportunities in your area including sports, events and social clubs. There may be a youth service that can provide further information. Local disability information services and support groups may also have details of activities and leisure opportunities. Contact a Family also produces a guide 'Holidays, play and leisure' which contains further information about accessing leisure opportunities.

BBC Ouch

<http://bbc.co.uk/ouch>

A website run by the BBC with fun web pages, podcasts, videos, news and quizzes, by disabled people for disabled people. Suitable for older teenagers and young people.

Money post-16

Benefits

When your child reaches 16 years of age they may be able to claim benefits in their own right. However, if they do you will lose any benefits you receive for them as your dependant, for example Child Benefit. Ring the helpline for more information and a copy of the guide 'Money when your child reaches 16 years of age'. The factsheet has a section about benefits a young disabled person can claim when they are 16. It is important that you get more information about

benefits before a child's 16th birthday, because you could lose money without proper advice.

Education Maintenance Allowance (EMA)

Educational Maintenance Allowance (EMA) is a weekly payment for young people in Scotland, Wales and Northern Ireland, who stay on in full time, non-advanced education. The amount of EMA will depend on your family income. If your parental income is above a certain threshold then no EMA is paid. Application forms are available from the school or college.

The 16 – 19 Bursary Fund has replaced EMA in England. A young person in receipt of DLA and ESA will get a guaranteed bursary of £1,200 a year so long they are on an eligible course. This depends on how the course is funded and so you will need to contact the course provider to check whether a bursary can be paid. If a student is on an eligible course but cannot get a guaranteed bursary (for example they don't get ESA) they can apply for a discretionary bursary instead. The amount and the duration will be at the discretion of the school or college.

For information on both EMA and the 16-19 Bursary fund please visit www.direct.gov.uk for details.

Wills and trusts

Making provision for the future is very important for families with a disabled young person. You can set up a trust

for your child to keep them secure. This will mean seeing a solicitor for expert advice. However, there is free information available which will help you decide what arrangements you might like to make.

The Disability Law Service

39–45 Cavell Street London E1 2BP
National advice line: 020 7791 9800
Textphone: 020 7791 9801
www.dls.org.uk

Offers a legal service that enables disabled people to access relevant information, clarify their rights and take appropriate action. They publish an information sheet 'Guidelines for trusts where there is a member of the family with a disability'.

Mind

PO Box 277, Manchester M60 3XN
Helpline: 0845 766 0163
www.mind.org.uk

The mental health charity MIND can also help. They can send you details of solicitors who specialise in wills and trusts and work in your area.

Wills and Trusts Team, Mencap

123 Golden Lane, London EC1Y 0RT
Tel: 020 7696 6925
Textphone: 18001 0808 808 1111
<http://tinyurl.com/yullxt>

Mencap produce a guide 'Leaving money in trust' on leaving money to people with a learning disability. They also publish other booklets including a list of specialist solicitors.

Further reading and useful contacts

The publications, websites and organisations listed here offer a good starting point for more detailed information.

Transition Information Network

c/o Council for disabled children,
8 Waleeley Street,
London, EC1V 7QE
www.transitioninfonetwork.org.uk

The Transition Information Network (TIN) is an alliance of organisations and individuals who come together with a common aim: to improve the experience of disabled young people's transition to adulthood. TIN is a source of information and good practice for disabled young people, families and professionals. It produces a free magazine for young people, 'My future choices' plus 'Getting a life' newsletter for professionals.

Progress

This is a magazine produced by Care Choices. It explores issues faced by many young people with disabilities and contains information, advice and ideas to help with looking to the future. Call the Contact a Family helpline for a free copy.

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

Growing up matters: better transition planning for younger people with complex needs (2007)

Commission for Social Care Inspection
33 Greycoat Street, London SW1P 2QF
Tel: 0845 015 0120
Text: 0845 015 2255
www.bipsolutions.com/docstore/pdf/16064.pdf

This study examines the experiences of young people with combinations of acute and chronic medical conditions, multiple and profound impairments, behavioural problems and learning difficulties. In particular it looks at the views and experiences of those who have been placed in residential care outside their home area.

Transition! Getting it right for young people (2006)

Available from DH Publications Orderline,
PO Box 777 London SE1 6XH
Tel: 0870 155 54 55
<http://tinyurl.com/2toby0>

This health publication is a useful good practice guide for professionals working with children and young people with chronic health needs.

Transition: moving on well (2008)

Available from DH Publications (as above)
<http://tinyurl.com/6cat43>

Good practice guide for health professionals and their partners working with young people with complex health needs or a disability, from the Department of health and the Department for Education.

Moving on Up

Helpline: 01246 541 675
www.movingonup.info

A website designed to be used by young people. Includes advice around learning and working; free-time, health and well being, as well as money, housing, culture and news and events. It is a good source of information for minority ethnic groups.

Special Educational Needs Code of Practice (England) (2001)

Castle View House, East Lane, Runcorn,
Cheshire WA7 2GJ
Tel: 0370 000 2288
<http://tinyurl.com/ypp4js>

This document published by the Department for Education, gives guidance on special educational needs. Early years settings, schools and LAs must have regard to it when considering a child's special educational needs (SEN).

Special Educational Needs Code of Practice Wales (2002)

The Publications Centre, Welsh
Government, Cathays Park, Cardiff
CF10 3NQ
Tel: 029 2082 3683
<http://tinyurl.com/6540pw>

This document, published by the Welsh Government, gives guidance on special educational needs. Early years settings, schools and LAs must have regard to it when considering a child's special needs.

Updated by Alex Burch

Social networking

Contact a Family is on Facebook and Twitter. Join us at:

Facebook

[www.facebook.com/
contactafamily](http://www.facebook.com/contactafamily)

Twitter

www.twitter.com/contactafamily

Podcasts

You can download podcasts from our website at:

[www.cafamily.org.uk/news/
podcasts.html](http://www.cafamily.org.uk/news/podcasts.html)

iTunes users can listen to our podcasts at:

www.cafamily.org.uk/itunes

Videos

You can watch videos on our **YouTube** channel at:

www.youtube.com/cafamily

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

Getting in contact with us

Free helpline for parents and families

0808 808 3555

Open Mon–Fri, 9.30am–5pm

Access to over 170 languages

www.cafamily.org.uk
www.makingcontact.org

Contact a Family Head Office:

209-211 City Road, London EC1V 1JN

Tel **020 7608 8700**

Fax **020 7608 8701**

e-mail **info@cafamily.org.uk**

Web **www.cafamily.org.uk**



Language Line
services

Other information booklets available

This guide is one of a series produced for parents and groups concerned with the care of disabled children. A full list of Contact a Family publications is available on request or can be downloaded from our website www.cafamily.org.uk

- Benefits, tax credits and other financial help (UK)
- Money when your child reaches 16 years of age (UK)
- Disabled children's services in England and Wales (England and Wales)
- Getting direct payments for your disabled child (England and Wales)

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