



contact a family
for families with disabled children



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 Children, Schools and Families' 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).

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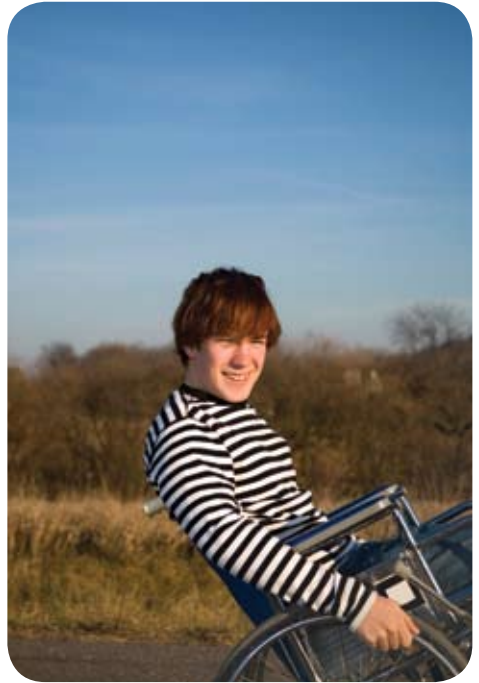
Starting to think about transition

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.

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 Connexions Service (Careers Wales in Wales) provides support for all young people of 13 to 19 years of age, but has a particular focus on supporting disadvantaged young people or those likely to underachieve, including those with special educational needs but without a statement.

They have a responsibility (a legal 'duty' in Wales) under section 140 of the Learning and Skills Act 2000, to make sure all young people who have difficulty transferring to further education

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or training, have a needs and provision 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.

If your child doesn't have a statement and isn't in contact with the Connexions Service or Careers Wales, you may want to arrange a meeting with them to discuss your child's options after 16. 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

'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)

person, their family, the school and the 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
- the Connexions Service in England or Careers Wales must be invited. A representative from Connexions and Careers Wales has an obligation to attend the review. In Wales, if a representative from Careers Wales 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.

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.

Issues the young person may need to discuss

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.

'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)

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 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

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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.

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

The Valuing People Person Centred Transition Reviews project is now working in most local authorities in England. More information about Valuing People, person centred planning and transition can be found at:

Web: <http://valuingpeople.gov.uk> or <http://www.learningdisabilitywales.org.uk> in Wales.

A guide to person centred planning is available from

The British Institute of Learning Difficulties (BILD)

Champion House, Green Street,
Kidderminster, Worcestershire DY10 1JL

Tel: 01562 723 010

Web: http://www.bild.org.uk/05faqs_5.htm

“Because my son has been educated at home, we haven’t had any of these ‘transition meetings’ yet we seem to be moving forward.”

Jane

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.

Professionals

- in advance of meetings, make sure you get information about other sources of help such as support groups, specialist agencies and medical information
- make a point of asking the young person what they want, then asking the parent if there is anything they would like to add
- listen to both the young person and the parent
- allow time for the parent to speak in the meeting.

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After the transition plan review meeting

Responsibility for the plan

The head teacher, in consultation with the Connexions Service (Careers Wales in Wales) must ensure that the transition plan is drawn up. The Connexions Service (Careers Wales) is responsible for overseeing how the elements of the plan relating to further learning, training or employment are put into action. 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 of Connexions must be invited to and attend the Year 9 review. A representative of Careers Wales must be invited and must make every effort to attend
- health authorities and trusts should be made aware of the review and can attend and contribute
- the 14+ Transition Review meeting takes place.

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 Connexions personal 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 of Careers Wales/Connexions 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 2000 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 Learning and Skills Council (LSC)

in England or the Welsh Assembly, 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)
- connexions/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.

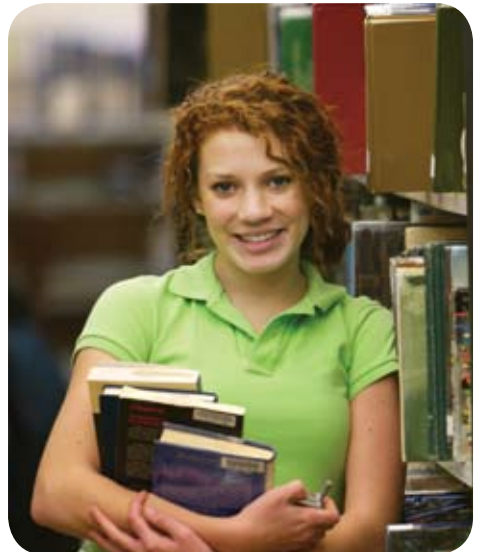
- **Higher education institutions**

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
- Programme-led Pathway course
- Personal and Community Development Learning.



For further information about post-16 education, contact:

Skill

Skill, Chapter House, 18-20 Crucifix Lane, London SE1 3JW

Tel: 0800 328 5050 (Tue, 11.30am-1.30pm; Thurs, 1.30-3.30pm).

Textphone: 0800 068 2422

Web: <http://www.skill.org.uk>

Skill is the National Bureau for Students with Disabilities. It provides individual support and publishes helpful information sheets for students wishing to undertake further or higher education or training, including information about funding.

LearnDirect

Tel: 0800 100 900

Textphone: 08000 568 865

Web: <http://www.learnirect.co.uk>

Provides general advice about courses anywhere in the UK.

Education Grants Advisory Service (EGAS)

501-505 Kingsland Road, London E8 4AU

Tel: 020 7254 6251

Web: <http://www.egas-online.org>

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

“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

Learning and Skills Council (LSC)

Cheylesmore House, Quinton Road, Coventry, CV1 2WT

Tel: 0870 900 6800

Web: <http://www.lsc.gov.uk>

Responsible for funding and planning education and training for over 16's in England. This includes further education, work-based training, school sixth form and adult and community learning, but not higher education.

The Welsh Assembly Government

Cathays Park, Cardiff, CF10 3NQ

Tel: 0845 010 3300

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

Has responsibility for funding, planning

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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.

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

Web: <http://www.jobcentreplus.gov.uk>

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 like WORKSTEP, the Job Introduction Scheme and Access to Work. Access to Work provides equipment and other services to support disabled people in their job. For more information contact your local Jobcentre Plus or visit their website

Careers Wales

Tel: 0800 100 900 (via LearnDirect)

Web: <http://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.

Connexions

Tel: 080 800 13 2 19

Textphone: 080 00 968 336

Web: <http://www.connexions-direct.com>

Government support service for young people of 13 to 19 years of age in England. The service aims to provide integrated advice, guidance and access to personal development opportunities and to support young people making the transition to adult life.

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 26, Severnside Trading Estate,
Sunmeadow Rd, Gloucester, GL2 5HS

Tel: 08445 617 445

Web: <http://www.afse.org.uk>

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'.

Disability Discrimination Act 1995

If your child has a disability, they may be covered by the Disability Discrimination Act (DDA). The DDA 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 DDA 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.

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

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- 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-CTRX, 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 social services department or a local disability organisation for details.

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

32-36 Loman St, Southwark, London,

SE1 0EE

Tel. 020 7922 8000

Carersline: 0808 808 7777 (Wednesday
and Thursday, 10am-12pm and 2-4pm)

Web: <http://www.carersuk.org>

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

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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 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
- holidays
- meals
- telephone equipment.

In the following sections we have signposted some of the core support

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.

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



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As your child goes through transition their needs may change and your roles as a carer may change too.

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.

Independent Living Fund (ILF)

ILF, PO Box 7525, Nottingham NG2 4ZT
Tel: 0845 601 8815
Textphone: 0845 601 8816
Web: <http://www.ilf.org.uk>

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.

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**

Health, housing and leisure for young people

Health

GP's 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
Web: <http://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
Web: <http://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

Stanelaw House, Sutton Lane, Sutton,
Witney, Oxfordshire, OX29 5RY
Tel: 0845 456 1497
Web: www.housingoptions.org.uk

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

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

Web: <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.

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



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. Your social worker, local citizen's advice bureau or welfare rights worker may also be able to offer advice and guidance. 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)

This is a weekly payment for young people who stay on at school, college or training after compulsory school age. EMA is dependent on household

income and is intended to help with the day-to-day costs of further education. It is paid directly into the young person's bank account and bonuses are available depending on the progress the young person makes. EMA is paid on top of, and does not affect, other household benefits. For further information please see Contact a Family's factsheet 'Education Maintenance Allowance' or contact:

England

Web: <http://ema.direct.gov.uk>

Helpline: 0800 121 8989

Textphone: 0800 056 5344

Wales

Web: <http://www.studentfinancewales.co.uk>

Helpline: 0845 602 8845

Textphone: 0845 603 1693

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

(Mon to Fri 10am-1pm and 2-5pm)

Textphone: 020 7791 9801

Web: <http://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
Web: <http://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
Web: <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
Web: <http://www.transitioninfonyetwork.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.

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
Web: <http://tinyurl.com/2dqfsz>

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.

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

Transition! Getting it right for young people (2006)

Available from DH Publications Orderline,
PO Box 777 London SE1 6XH
Tel: 0870 155 54 55
Web: <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)
Web: <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 children, schools and families.

Trans-active

4 Swan Courtyard, Coventry Road,
Birmingham, B26 1BU
Tel: 0121 707 7877
Web: <http://www.trans-active.org.uk>

Trans-active is a project by Mencap in which teenagers with and without severe learning disabilities work together. The project enables people with disabilities to work through their options by using multimedia to explore and communicate choices. The project is about using and giving support, making plans, making friends and having fun.

Moving on Up

Helpline: 01246 541 675 (Mondays and Wednesday, 10am-12pm)

Web: <http://www.movingonup.info>

A website designed to be used by young people. Includes advice around learning and working; free-time, health and wellbeing, 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)

Web: <http://tinyurl.com/ypp4js>
or write to: Department for Children,
Schools and Families, PO Box 5050,
Annesley, Nottingham NG15 0DL
Tel: 0845 602 2260 (Option 4)

This document published by the Department for Education and Skills (now known as the Department for Children, Schools and Families), 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)

Available to download from
Web: <http://tinyurl.com/6540pw>
or write to: The Publications Centre, Welsh
Assembly Government, Cathays Park,
Cardiff CF10 3NQ
Tel: 029 2082 3683
Web: <http://new.wales.gov.uk>

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

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Contact a Family is now on Facebook, MySpace, Bebo and has an office in Second Life.

Join us at:

MySpace

www.myspace.com/contactafamily

Bebo

www.bebo.com/contactafamily

Facebook

www.facebook.com

and search for 'Contact a Family'

Second Life

You can find our Contact a Family virtual advice office in Second Life on Aloft Island 19.40.22 (PG) or visit <http://tiny.cc/P9A5I> to teleport there directly

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

Getting in contact with us

Free helpline for parents and families

0808 808 3555

Textphone

0808 808 3556

Open Mon–Fri, 10am–4pm;

Mon, 5.30–7.30pm

Access to over 100 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**

Email **info@cafamily.org.uk**

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



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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