



contact a family
for families with disabled children



Preparing for adult life and transition - Scotland

Information for families

Scotland

Incorporating **The Lady Hoare Trust**

Introduction

Leaving school and moving into adulthood is a challenging time for all young people with disabilities and their parents. What 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 may seem to be about to fade away.

For these reasons it is vital that parents and their children plan for transition to adult services and adult life as early as possible. This guide aims to help by bringing together some of the main issues that parents and young people need to think about. It is written for parents with children around the age of 14 as this is the age when planning for this transition process should normally begin.

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Planning for leaving school

Although you and your child might already have discussed plans for their future, formal transition planning usually begins at school. Under the Education (Additional Support for Learning) (Scotland) Act 2004, education authorities must do certain things to help all young people with additional support needs to make the transition from school to post-school life successfully.

Education authorities must request information from agencies likely to be involved with the child or young person on leaving school. These agencies could be:

- a local authority (council)

- an NHS board
- Careers Scotland
- a college or university.

Information is requested so that the education authority can think about whether the child is getting the right support at school to prepare them for moving on and make sure there is a good match between this and the support they will receive once they have left school. This must be completed at least 12 months before the child or young person is expected to leave school. Planning, therefore, should begin far earlier than this.

Some pupils may need at least two years to prepare for leaving school, for example those with complex needs who need co-ordinated support or pupils who need to make a very gradual transition to help them get used to a new environment.

Education authorities must also pass on information to the other agencies no later than six months before the child or young person is due to leave school. This will include the expected leaving date as well as any other information relevant to the support the young person will need, such as telling a university about the kind of learning support that has been in place at school or passing on information about care needs to the social work department.

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

Involving parents and young people

Education authorities must ask for, and take account of, both your and your child's views about leaving school and post-school opportunities during the transition process. This should be an ongoing dialogue with both you and your child being involved at each stage.

How parents can contribute to transition planning

You have a vital role in collecting relevant information because you know all the important people and activities in your child's life and can help them understand the choices available.

It is also helpful to think about your input as a parent and carer. How can you contribute to your child's personal and social development? Will your child's care needs change as he or she gets older? How do you see your child's future?

Once they reach the age of 16 young people assume their own rights under the Additional Support for Learning Act. Education authorities must seek and take account of their views and young people have the right to advocacy and the help of a supporter. However, you should continue to be involved in the planning process so that you can help your child.

How the young person can contribute

The school must make sure that your child has all the information they need to make decisions about post-school options such as training or

work placements and further or higher education.

Some young people find it helpful to talk to someone they already know and trust such as a teacher, social worker or careers officer. Some will need help to express their views and to make decisions and the education authority should provide this. Support could be provided in a number of ways depending on a child's needs, for example person centred planning could be used or a supporter or advocate appointed to help them take part in meetings.

It is very important that young people, as much as is possible, have a chance to share their concerns and ideas - both inside and outside the family. 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.

It is helpful to start keeping a record of 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.



How transition planning is managed

There is no standard format for the transition process other than the timescales for an education authority to ask for and pass on information to other agencies and the requirement to involve you and your child. Procedures may vary depending on where you live and on your child's additional support needs. The process might involve a series of discussions between the lead person and your child, you and others involved. A meeting might be called where you, your child and all the professionals working with your child meet together to talk about future plans. The education authority might produce a written transition plan but there is no requirement to do so.

Education authorities should provide clear information to you and your child about

what will happen, when it should happen and who is responsible. The authority might appoint a key worker, usually one of the professionals working with your child, to act as a single point of contact for you and the other professionals. If your child has a co-ordinated support plan (CSP) the co-ordinator will take the lead in transition planning.

Contact a Family's guide 'Additional Support for Learning – Scotland' has further information about additional support for learning including co-ordinated support plans and what to do if you disagree with the education authority about support for your child. Copies are available from the Contact a Family helpline, Tel: 0808 808 3555.

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The planning process should be monitored by the lead person and reviewed if there is a change of circumstances or the child or young person asks for an alteration to be made. If your child has a CSP the education authority must review it at least every 12 months. The review should include transition planning as well as assessing how effective the planning is.

Support for young people during transition

The support your child needs as they prepare to leave school will vary according to their needs, and could include:

- more emphasis on life skills and confidence building in the classroom
- a work experience placement
- attending college one or two days per week while still at school
- starting to use specialist technology at school which will be used at work or at college.

Education authorities must do certain things to help all young people with additional support needs to make the transition from school to post-school life successfully.

Information for both parents and young people about all aspects of additional support for learning, including preparing to leave school is available from:

Enquire

The Scottish Advice Service for Additional Support for Learning,
Tel: 0845 123 23 03
Web: <http://www.enquire.org.uk>

Further or higher education

There are various options for young people who want to continue their education after school:

- further education and training in colleges
- independent specialist colleges
- higher education at either a college or university
- open or distance learning.

Successful transition planning will have made sure that the young person has a clear understanding of what educational opportunities exist after leaving school. The choice of study will clearly depend on the type of course the young person wants to take and where the course is being run. Individual institutions should be contacted for information about courses and support services.

Every college or university should have a member of staff who advises students who need additional support. It is important for potential students to visit the college or university they are thinking of joining so that they can meet staff and



other students and discuss their support needs.

Learn Direct

Tel: 0800 100 900

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

Provides general advice about courses anywhere in the UK.

Skill Scotland

Tel/Textphone: 0800 328 5050

e-mail: admin@skillscotland.org.uk

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

Skill is the National Bureau for Students with Disabilities. It provides information and advice for disabled people in post-16 education, training and employment, and those who work with them. 'Scotland: Opportunities at 16' is an excellent summary of the main issues facing young people as they leave school. All Skill leaflets are available on their website.

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

Disability discrimination

If your son or daughter has a disability and has been discriminated against in education, employment or services this can be challenged. The young person does have to have a disability as defined in the Disability Discrimination Act 1995:

‘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’.

More information on how this applies in schools can be found in our guide ‘Additional Support for Learning - Scotland’. In regard to post-16 education this Act applies to:

- further and higher education institutions
- education authorities
- schools

Part 4 of the Act covers education including:

- admissions and enrolments, including when enquiring about and applying for a course
- student services, including teaching facilities, work placement, outings and trips, examinations, leisure and social facilities
- qualifications
- exclusions.

If you believe your son or daughter has been discriminated against for a reason related to their disability contact:

Equality and Human Rights Commission
(formerly the Disability Rights Commission)
Freepost RRL-GLB-UJTA
The Optima Building, 58 Robertson Street
Glasgow G2 8DU
Tel: 0845 604 5510 (Mon-Fri, 9am-5pm)
Text: 0845 604 5520
Fax: 0845 604 5530
Web: <http://www.equalityhumanrights.com>



Employment and training

Not all young people will want to move on to further or higher education. Their preferred option may be to work. In this case they may need specialist advice about training and employment opportunities. There are a number of agencies and people who can be consulted:

- **Jobcentre Plus**

They can provide a range of services. A disability employment adviser (DEA) can provide support to people who are finding it difficult to get a job due to their disability. They can help with an employment assessment to produce an action plan for getting a job and provide further details about WORKSTEP and the Job Introduction Scheme. Through the Access to Work (AtW) scheme disabled people can access a communicator for interviews, alongside a range of support once in work. For more information contact your local Jobcentre Plus or see Web: <http://www.jobcentreplus.gov.uk>

- **Careers Scotland**

This service provides careers and learning information, advice and guidance to young people and adults in Scotland. It has information on training programmes for young people, which involve work-based learning or placements. Careers Scotland can also help with student applications to colleges and universities. Tel: 0845 8502 502 for details of your local service. Web: <http://www.careers-scotland.org.uk>

Through the Access to Work scheme people with disabilities can access a communicator for interviews, alongside a range of support once in work.

- **Adult day centres**

Some young people may need the support and training offered by day centres. These are usually run by social work departments, but may be run by voluntary organisations. Such centres offer on-going training in areas such as independent living and work skills. If a placement is offered it could be short or long-term depending on a person's need. Most users are aged 19 or over. Referral for a placement is through a social worker.

- **Supported employment**

The Scottish Union of Supported Employment works with employers to provide support which enables disabled people to get jobs and stay in long term employment. It has local points of contact throughout Scotland. For further information Tel: 0131 539 4967 or Web: <http://www.suse.org.uk>

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Community care services

Community care legislation

Up to the age of 18 the needs of your son or daughter are assessed under the Children (Scotland) Act. From the age of 16 there is a transfer to adult services. Support for disabled adults is provided for under a range of community care legislation. A vital part of this legislation is the right of those who need support to have a full assessment of need. This assessment should look at a person's needs as a whole and not take each one separately. This assessment should be linked up with the work already undertaken in the transition plan.

Local authorities are required to identify disabled school leavers and assess their needs for social work services. 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. Local authorities must take into account a carer's ability to continue providing care for the disabled young person.

Social work must publish details of the services they provide and inform disabled people about support available from themselves or appropriate organisations. Assessments of both carers and the cared for person are the responsibility of your local social work department. For more information refer to our guide, 'A guide to assessments and services in Scotland'.

Carer's assessment

As a parent of a disabled young person you are entitled to a carer's assessment. This is undertaken by social work 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 work can provide to support you. As your child goes through transition his or her needs may change, and your role as a carer may change too.

A parent can ask for an assessment at any time so long as they are providing care on a 'substantial and regular' basis. The

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carer's assessment specifically focuses on you as a parent and your needs.

Social work should discuss with you various issues such as the help your son or daughter needs and whether there is anyone else who helps, or if you are providing all of the care. The assessment should also consider your well-being, including health and safety issues, and important commitments such as relationships and employment. The aim of an assessment is to give you a chance to tell social work about the things that could make looking after your son or daughter easier for you.

For further information on assessments ring the Contact a Family helpline, Tel: 0808 808 3555.

Carers Scotland also produce a useful range of publications for carers.

Carers Scotland

91 Mitchell Street,
Glasgow G1 3LN.

Tel: 0141 221 9141

e-mail: info@carerscotland.org

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

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 school. 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 state what other services should exist if the person is to be properly supported. This ensures that transition planning for each

young person is focussed on their needs and helps local authorities to plan future services more effectively.

Direct payments

Local authorities can give payments, instead of services, to disabled people to buy in the services they have been assessed as needing. Local authorities must offer the choice of a direct payment to anyone who is eligible. Direct payments are seen as a way of increasing choice and flexibility in how your child's needs are met. If a young person is under 16 direct payments will usually be made to the parent.

When a child becomes 16 she or he can receive payments in their own right to allow them to buy in the services they have been assessed as needing. If a 16 or 17 year old lacks the capacity to consent to a direct payment, then a parent can do this on their behalf. In order for a disabled adult aged 18 or over to receive



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direct payments, he or she must have the capacity to manage them (either alone or with assistance). Scottish Executive guidance reminds local authorities that they should not exclude whole groups (e.g. people with learning difficulties) by simply assuming they do not have the competency. Instead local authorities should examine whether a person would have the capacity to manage payments if sufficient support were provided.

Where a young person aged 18 or over clearly lacks capacity, it is possible for a parent who has relevant powers under the Adults with Incapacity Act to manage direct payments on their son or daughter's behalf. For more information about the Act ring the Contact a Family helpline.

A direct payment can only be used to purchase services your child has been assessed as needing. The amount given should be enough to meet all the costs involved. If you decide to employ someone directly this should include tax

and national insurance as well as the fee for a police check. Social work may ask you to make a contribution towards the package of care that your direct payments fund. This charge will be calculated in the same way as if they had arranged services for your child.

The general rule is that you cannot normally use a direct payment to employ a close relative. However social work can agree to make an exception to this rule, and allow you to employ a close relative if they believe that this is necessary in order to meet your disabled child's needs. Social work can agree to this even if that close relative shares your child's household. Ring our free Helpline for more information about direct payments.

Short breaks

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

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

As well as residential short breaks there may be a local family link or befriending scheme linking young people to a family or volunteer for short breaks.

Shared Care Scotland can give more information about schemes in your area, Tel: 01383 622462.



Independent Living Funds

This is an independent discretionary trust fund covering the UK. The Fund (ILF) works in partnership with local authorities to organise joint care packages that are a mixture of services from the local authority and cash from the Fund to enable disabled people to buy in extra care. The Fund is open to disabled people aged between 16 and 65 who receive the high rate care component of Disability Living Allowance. There are various other conditions which must also be met.

To find out about eligibility, contact your social work department and ask for information about ILF. On application, a visiting social worker from the Fund will arrange a joint visit to discuss care needs and agree what is needed. The Fund's social worker will then make a written report with recommendations to the Fund.

For more information about the Fund, contact:

ILF

PO Box 7525

Nottingham NG2 4ZT

Tel: 0845 601 8815

e-mail: funds@ilf.org.uk

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

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

Health services

Family doctors remain the first point of contact as far as providing primary health care services to individuals is concerned. Many paediatricians will continue to see their patients into adulthood particularly if there is a developmental delay or rare disorder.

It is important that a health professional is involved in transition planning, for example the school doctor. The GP should be the first point of contact after leaving school if physiotherapy and speech therapy services are required. This need should have been identified in transition planning so that all the services are aware before an individual leaves school.

It is important that a health professional is involved in transition planning, for example the school doctor. The GP should be the first point of contact after leaving school if physiotherapy and speech therapy are required.

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

Help with mobility aids should come via your GP, community nurse or occupational therapist.

FAIR Multimedia

95 Causewayside
Edinburgh EH9 1QG
Tel: 0131 662 1962
e-mail: multimedia@fairadvice.org.uk
Web: <http://fairadvice.org.uk>

FAIR (Family Advice and Information Resource) Multimedia publishes a range of health leaflets specifically designed for people with learning disabilities.

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 including:

FPA Scotland

Unit 10
Firhill Business Centre
76 Firhill Road
Glasgow G20 7BA
Tel: 0141 948 1179
e-mail: fpadirect@fpa.org.uk
Web: <http://www.fpa.org.uk>

Contact a Family has published a series of booklets looking at how being disabled might impact on issues around sex and relationships for young disabled people.

There are three booklets, (one for parents, one for young people and one for teachers) which can be obtained from the helpline on Tel: 0808 808 3555 or e-mail: helpline@cafamily.org.uk

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 work 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 Options

Tel: 0845 456 1497

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

Provide advice and information for people with learning difficulties and their carers.

Ownership Options

Tel: 0131 661 3400

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

Aims to create equal access for disabled people to mainstream home ownership in Scotland. Produces a series of leaflets on different aspects of home ownership.

Ring our helpline for details of local housing advice agencies.

housing, mainstream accessible housing and through services such as home adaptations and advice. Each local authority should have a 'Supporting People Team' responsible for planning and funding housing support services for people who require assistance in living independently.

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 transition planning. There are several options that can be considered, in particular a placement in a residential home or an independent living scheme. Such provision is available through the statutory, voluntary and private sectors.

Your first point of contact should be your social worker although you can contact voluntary and private organisations for information and advice. 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.

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

Leisure

Access to leisure opportunities is an important part of any individual's life. It is vital therefore that transition planning records a young person's leisure interests and aspirations, and that appropriate plans are then made.

Any given area will have a range of leisure opportunities, for example sports centres and clubs. To find out more contact your local library. Different voluntary agencies will also have details of specific activities, in particular those that are accessible for disabled people. Contact your Local Council for Voluntary Services or visit Web: <http://www.youthinformation.com> for details of different organisations. The local authority youth service should also offer opportunities - contact your local authority youth office. If you have a local disability information service, consult them.

Contact a Family also produces a guide 'Holidays, play and leisure' giving more information.

When your child reaches 16 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.



Benefits

When your child reaches 16 they may be able to claim benefits in their own right such as Incapacity Benefit or Income Support. However, if they do you will lose any benefits you receive for them as your dependant, for example payments of Child Benefit and Child Tax Credit. Ring the Contact a Family freephone helpline on Tel: 0808 808 3555 (Mon-Fri, 10am-4pm; Mon, 5.30pm-7.30pm) for detailed advice and copies of our guides 'Benefits, tax credits and other financial help' and 'Money when your child reaches 16 years of age'. Your social worker, local citizen's advice bureau or welfare rights worker may also be able to offer advice and guidance.

Employment and Support Allowance (ESA)

From October 2008 a new benefit called the Employment and Support Allowance (ESA) will replace Incapacity Benefit and Income Support for people who are unfit to work. For more up to date information call our free helpline.

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.

Enable

6th Floor
7 Buchanan Street
Glasgow G1 3HL
Tel: 0141 226 4541
e-mail: enable@enable.org.uk
Web: <http://www.enable.org.uk>

Have a useful booklet for parents in Scotland, 'Making a will: What to consider when leaving money to a person with a learning disability'.

Adults with Incapacity (Scotland) Act 2000

It is worth noting that when a son or daughter reaches 16 and becomes an adult, parents usually have no *legal* right to decide where he or she should live or what they should do. However, if your son or daughter has a disability which prevents them from being able to make decisions for themselves, it is possible to apply for specific powers under the Adults with Incapacity (Scotland) Act. This can include the authority to make decisions about someone's personal welfare. Such powers are only granted where a Sheriff is convinced they are absolutely necessary.

Please note that the power to consent to specific forms of medical treatment is not covered.

For more information about the powers available under this Act contact:

Office of the Public Guardian

Tel: 01324 678 300
e-mail: opg@scotcourts.gov.uk
Web: <http://tinyurl.com/2spjyy>

or Enable

Tel: 0141 226 4541
e-mail: enable@enable.org.uk
Web: <http://www.enable.org.uk>

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

Further reading

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

Transition Information Network

Web: <http://www.transitioninforonetwork.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.

Progress

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

Trans-active

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. Teenagers with learning disabilities need to make life choices about school, college, work, their social time and where they might live. The project enables disabled people 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

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, news and events.



Contact a Family would like to thank Department of Children, Schools and Families, Children, Young People and Families Grant Programme for funding for this publication.

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/P9A5l> 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**



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

- A guide to assessments and services in Scotland (Scotland)
- Dealing with debt (Scotland)
- Additional support for learning (Scotland)
- A parents' guide to direct payments in Scotland (Scotland)
- Money when your child reaches 16 years of age (UK)



Family Fund
helping disabled children

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London EC1V 1JN
Registered Charity Number: 284912
Charity registered in Scotland No. SC039169
Company limited by guarantee
Registered in England and Wales No. 1633333

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