



Preparing for adult life and transition – Scotland

Information for families

Scotland

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, as amended in 2009, 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
- Skills Development 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.

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

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.

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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?

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.

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.

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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Education authorities should provide clear information to you and your child about what will happen, when it should happen and who is responsible.

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 lead professional, 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.

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.

If you or your child thinks the education authority has not followed the correct procedures you have a right to appeal to the Additional Support Needs Tribunals. This could be in relation to gathering information about your child, involving you and your child in the process and sharing this information with relevant agencies. For a Guide to the Additional Support Needs Tribunal telephone 0845 120 2906, or visit their website at www.asntscotland.gov.uk





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.

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

Enquire

Children in Scotland
5 Shandwick Place, Edinburgh EH2 4RG
Tel: 0845 123 23 03
www.enquire.org.uk

Lead Scotland
Tel: 0800 999 2568
Email: info@lead.org.uk
www.lead.org.uk

Lead Scotland seeks to widen access to learning for disabled people and carers in Scotland. It offers information and advice on opportunities including community learning, volunteering, apprenticeships and education. A booklet called *Post-school learning choices in Scotland* is available from the Lead website or by calling Lead's freephone helpline.

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Web: **www.cafamily.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.

Skills Development Scotland

Tel: 0800 917 8000

www.skillsdevelopmentscotland.co.uk

Provides general advice about learning options.



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

Employment and training

Not all young people will want to move onto 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 people with disabilities can access a communicator for interviews, alongside a range of support once in work. For more information contact your local Jobcentre Plus or see www.jobcentreplus.gov.uk

▪ My World of work, Scotland

This service, offered by Skills Development Scotland, 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. You can also explore careers and build your CV online.

Tel: 0808 100 105

www.myworldofwork.co.uk

▪ 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.

For further information see

www.susescotland.co.uk

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



Disability discrimination

If your child has a disability, they may be covered by the Equality Act 2010. The 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, discrimination occurs when:

- a disabled person is treated less favourably than someone else because they are disabled
- a disabled person is treated less favourably than someone else because of something arising from their disability and the treatment cannot be justified
- a particular provision, criterion or practice is applied to a disabled person, which puts them at a disadvantage and this treatment cannot be justified

- there is a failure to make 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 effect on a person's ability to perform normal day-to-day activities'.

Disability discrimination at school

More information on how this applies in schools can be found in our guide 'Additional Support for Learning – Scotland'.

Rights in post-16 education

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

- further and higher education institutions
- education authorities
- schools

and covers:

- admissions, including when enquiring about and applying for a course
- teaching, learning and other student services provided mainly for students, including work placements, outings and trips, leisure facilities and student accommodation
- exclusions.

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

- the recruitment process

- the terms and condition or 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

151 West George Street
Glasgow G2 2JJ
Helpline: 0808 800 0082
Textphone: 0808 800 0084
www.equalityhumanrights.com/scotland

Help with care needs

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 they should be transferred 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 their needs. 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 planning.

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

As a parent of a disabled young person you are entitled to a carer's assessment.

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*** – call the Contact a Family helpline for a copy or download it from our website.

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

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goes through transition his or her needs may change, and your role as a carer may change too.

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 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.

A parent can ask for an assessment at any time so long as they are providing care on a 'substantial and regular' basis. The carer's assessment specifically focuses on you as a parent and your needs.

For further information on assessments ring the Contact a Family helpline on freephone 0808 808 3555.

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

Carers Scotland

Tel: 0141 445 3070

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 direct payments, he or she must have the capacity to manage them (either alone or with assistance). Scottish Government guidance reminds local authorities that they should not exclude whole groups (e.g. people with learning disabilities) 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. See the 'Making Decisions' box on page 17 or ring the Contact a Family helpline for further information.

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 you.

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 freephone helpline for more information about direct payments or to request a copy of our booklet, 'A parents' guide to direct payments in Scotland'.

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.

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

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
www.sharedcarescotland.org.uk

Health services

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 developmental delay or rare disorder.

It is important that a health professional is involved in transition planning, 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 speech therapy services are required. Any therapy required should have been identified in transition planning so that all the services are aware before an individual leaves school.

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.

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

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

Family Advice and Information Resource (FAiR)

95 Causewayside, Edinburgh
EH9 1QG
Tel: 0131 662 1962
www.fairadvice.org.uk

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

fpa

Tel: 0845 122 8690
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.



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.

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, 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.

Capability Scotland

Tel: 0131 337 9876

www.capability-scotland.org.uk

Runs different services across Scotland to support people living as independently as possible.

Housing Options Scotland

Tel: 0131 247 1400

www.housingoptionsscotland.org.uk

Advise disabled people and carers on, and support them through, the design, financial and legal processes involved in buying or renting a property.

Ring our helpline for details of local housing advice agencies.

Freephone helpline: **0808 808 3555**

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

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.

Leisure

Access to leisure opportunities is an important part of any individual's life. It is vital that transition planning records a young person's leisure interests and aspirations.

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

www.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 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 payments of Child Benefit and Child Tax Credits. Ring the helpline for more information and a copy of the guide '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. 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 contact the school, college or local authority or visit www.emascotland.com



Making decisions

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 2000. 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

www.publicguardian-scotland.gov.uk/

or Enable

Tel: 016 737 000

www.enable.org.uk

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

INSPIRE House, 3 Renshaw Place,
Eurocentral, Lanarkshire, ML1 4UF

Tel: 016 737 000

www.enable.org.uk

Enable have a useful booklet for parents in Scotland, *Making a will: What to consider when leaving money to a person with a learning disability*. The booklet is also available to download from their website.

Further reading and useful contacts

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

Transition Information Network

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

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adulthood. TIN is a source of information and good practice for disabled young people, families and professionals.

Progress

www.progressmagazine.co.uk

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.

Moving on Up

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.

Moving on to adult life: A resource pack written by families for families

A resource pack for young people with disabilities and their families. The pack has suggestions on things families can do to make the move to adult life easier. Has stories about young people and their families and notes on where to get more information. Includes a CD-ROM and is available to buy from Outside the Box, £19.99, Tel: 0141 445 3062
www.otbds.org

Social networking

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

Facebook

www.facebook.com/contactafamily

Twitter

twitter.com/contactafamily

Podcasts

You can download podcasts from our website at: www.cafamily.org.uk/news/podcasts.html

iTunes users can listen to our podcasts at: <http://bit.ly/96EVT>

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**

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

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



Language Line
services

Registered Office: 209–211 City Road,
London EC1V 1JN
Registered Charity Number: 284912
Charity registered in Scotland Number: SC039169
Company limited by guarantee
Registered in England and Wales Number: 1633333
VAT Registration Number: GB 749 3846 82

Other information booklets available

This guide is one of a series produced for parents and groups concerned with the care of disabled children. Other guides include:

- A guide to assessments and services (Scotland)
- Additional support for learning (Scotland)
- A parents' guide to direct payments (Scotland)
- Personal Independence Payment and other benefits at 16 (UK)
- Understanding your child's behaviour (UK)
- A guide to dealing with bullying (UK)

A full list of Contact a Family publications is available from our helpline, or can be downloaded from our website www.cafamily.org.uk

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