



Understanding Chromosome & Gene Disorders

UniquE, Understanding chromosome and gene disorders  
The Stables, Station Road West, Oxted, Surrey RH8 9EE, United Kingdom  
Tel: +44(0)1883 723356  
[info@rarechromo.org](mailto:info@rarechromo.org) | [www.rarechromo.org](http://www.rarechromo.org)

Join UniquE for family links, information and support. UniquE is a charity without government funding, existing entirely on donations and grants. If you can please make a donation via our website at [www.rarechromo.org](http://www.rarechromo.org) Please help us to help you!

Our thanks to all of our parents for their contributions to this guide.

This guide was compiled by UniquE.  
The medical information within was reviewed and verified by Polly Schofield, Lead Nurse for Transition, Royal Berkshire NHS Foundation Trust and Dr Catherine Tuffrey, Consultant Paediatrician, SOLENT NHS TRUST.  
The legal information within was reviewed and verified by Philip Lansberry, Partner and Head of Legal. For and on behalf of Kreston Reeves Private Client LLP.

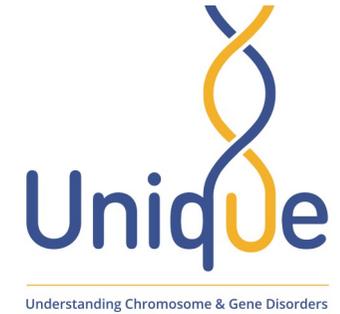
Contains public sector information licensed under the Open Government Licence v3.0.

Version 2 (MM)

Copyright © UniquE 2019

Rare Chromosome Disorder Support Group      Charity Number 1110661

Registered in England and Wales      Company Number 5460413



# Transition (from child to adult services)



## Transition from child to adult services guide

For parents of children with a rare chromosome or gene disorder, transition can be a very scary and difficult time. Having come through the 'school years' with your child, the thought of them leaving the safety and security of school and school life is very worrying. I myself have been through the transition process with my son Robert (who has a disorder called idic 15) and while Rob was blissfully unaware of what was about to happen, I found it very daunting. Even though Rob had a care plan in place, we slipped through the net when it came to being informed about his choices and were left with little knowledge about what would happen when Rob left school and what support was available; it was very basic to say the least. I kept thinking there must be an easier way of getting the support and help you need, so I was determined to find and put together at least the basic information needed to help other families. This guide has been a long time in the planning! I had always planned to write it once my son had gone through transition and come out the other side! Rob left school at the age of 19. He is now well and truly through transition and settled into daily life. He had a statement formally entitling him to learning support from the age of 2 and spent 17 years in the special educational needs system, first in the nursery assessment unit and then in primary/secondary school and then further education (all on the same site). Most of what I have learned along our transition journey has been via other parents I know; or have met via the two Facebook groups I set up (thank you to all of them – they are founts of knowledge!). So this guide is to help arm parents of children with chromosome and gene disorders get the right information; to allow them to ask professionals the right sorts of questions and to help their child's transition to adulthood run as smoothly as possible.

*~ Written by Marion, Unique Family Support Officer and mum to Robert (aged 25 at time of writing in 2019).*



## Notes

## Notes

## Index

What is transition?.....	4
Annual review meeting.....	5
Post 16 and further education.....	6
16-19 bursary.....	9
Transition links.....	10
Local links.....	12
Local offer.....	13
Respite/short breaks.....	14
Personal budgets/direct payments.....	15
Benefits.....	17
Person centred planning.....	19
Advocacy.....	20
Personal communication passports.....	21
Banking .....	22
Housing and council tax.....	23
Legal information - best interests decisions.....	25
Court of protection, deputyship, Mental capacity act...28	
Care providers.....	31
Health and Social care.....	32
Health checks.....	33
Going into hospital.....	35
Mental Health.....	36
Bereavement.....	37
Wills and Trusts.....	38
Personal, social and health education and sexual and relationships education.....	39
Grants.....	41
Leisure.....	42
Travel training.....	44
Blue badge.....	45
Learning to drive.....	45
Other Links.....	47
A-Z Glossary of terms.....	50
Parent quotes.....	52
Notes.....	54

## What is transition?

The dictionary definition of transition is:

*'a passing or passage from one condition, action, or (rarely) place, to another';* so in other words it means 'journey'. In this guide we refer to the transition from child to adult services.

The transition process for children with special needs should start with the year 9 annual review and transition plan, which outlines the support provided for your child from age 14 through to the age of 25 if needed. If your child already has an Education Health and Care [EHC] plan, he or she will have a 'transition plan' drawn up in year 9. This helps to plan for their future after leaving school. The transition plan is reviewed each school year. Your local authority should make sure that your child gets the support they need and will work with social services and careers advisors before your child leaves school. Starting in year 9, it may seem like planning for transition is a generous timeframe to work towards the support needed. In my and other parents' experience nothing much seems to happen in the years 9-11; you have an annual review (or the EHC plan equivalent) to discuss your child's progress at school as usual. Once your child reaches 15 years old, is probably the time when the planning starts in earnest. The term 'transition' is used to describe the process of moving from childhood into adult life. This time can be exciting but also challenging for the children and their parents. There will be lots of changes and choices that need to be made about the future. You may be receiving support from a number of different agencies, including health, social care and education services, and these will all change. Parents of children with chromosome and gene disorders will probably find transition the most challenging time in their lives since their child's diagnosis.

**Blum's definition of medical transition (Blum et al 1993, Journal of Adolescent Health) 'The purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child - centred to adult orientated health care services'.**

### 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.

*"The transition, although last minute, has been really smooth so far. I knew I was in good hands when the social worker from the Adult team said she was going to apply for two PA's 5 hours daily, 7 days a week. She said that you have to ask for the best straight off so that you are in a better place for bargaining. We got the 5 hours, 7 days a week without a problem and as it is via self-directed support. I don't have to use it every week and can bank it and get a holiday...yippee!!! It doesn't start until the beginning of July when he leaves school but finally he will be able to have fun out and about, without his mum all the time. Also in relation to the welfare part of the guardianship: if you use any kind of monitor so that you are able to see your child whilst they are sleeping this is seen as a deprivation of liberties in regards to care!!! Even though I use it because a) he has seizures, some of which are silent to begin with, or he just stops breathing and b) he is on non-invasive ventilation and the machine does not have an alarm. It makes no difference your reasons why, if it's not included in your Guardianship in Scotland then you will have difficulties with respite/social work etc. So now we have to go back to court to have a variation added in, less than a year after the guardianship was granted."*

*"I went to welfare rights when S was coming up 18 and they helped and supported me through transition with benefits but one word of advice I would give parents coming up to transition is if you have a child with medical problems, hospital appointments/visits etc make sure they are transferred over to adult services. S got lost in the system and it took quite a while to pick up all his appointments. Also check out adult respite, it is run completely differently to children's respite."*

*"We're wading our way through transition which seems a very slow journey here. 'Money advice unit' - children's (up to 19 years) have been invaluable to us for helping apply for ESA & DLA/PIP! Phoning us to make sure we've had replies & that they've moved smoothly! and when our daughter got put in a work group [ESA], which on a good day was hilarious, but on a bad day is so painful, a lady phoned up DWP & sorted it! It's like the blind leading the blind!!"*

## More Parent quotes

*“Planning for transition is essential and the earlier it begins the better prepared your child and the appropriate services will be. Do your homework and find out what support and services are available locally. Make sure you have a named transition support worker who will attend EHC plan reviews, as it is vital to ensure that adult services know about your child and his/her needs. You can also ask for an advocate to be present to support you if you feel this is needed. If you’ve not already done so, ask for a carer assessment to identify your own needs as this may lead to support for you. Check out how health and social care will work together (if your child has medical and health needs) and ensure that you know who is funding which element of any agreed care package. This is important as there have been instances of social services and health services arguing that a service is care-related - therefore needs funding by adult care and vice versa.”*

*“Re: 19 to 25s - the plan doesn't guarantee education beyond 19, but if the young person could benefit from further education and training to reach outcomes, the plan can and should remain in place.”*

*“I would also say if as a family you have managed without support from social services then think about asking for help from age 14/15. It is very difficult to get support as an adult if your son or daughter hasn't had any as a child. Also try and ask about transition from age 16/17. I think once Social Services know that you are on the ball, they tend not to let things slide as much.”*

*“We have received a direct payment from social care services since my son was 19. It pays for his day care and his personal assistants. We use the agency for our county to do the payroll service for us (for a fee which comes out of his DP's) and after setting up a separate bank account in my name (he lacks capacity), I manage his support and payments myself.”*

*“Transition expectations are naturally high for most families, but often fall miserably short in reality.”*

## The annual review meeting

Don't be afraid to ask the professionals attending the meeting, questions. Keep a notebook and pen beside you at home and every time you think of a question to ask them, write it down. Take the notebook with you to annual review meetings and ask those questions, making a note of the answers, as sometimes not every single relevant thing is written down in reports (although it should be). If you are not certain what something means, don't be afraid to ask the professionals to repeat or explain what they said, or ask them to write it down for you in your notebook.

The basic duty owed to disabled young people in transition, across all service areas, is that the responsible statutory body must assess their needs and put in place a plan to ensure that those needs are met. If your child is able to speak for themselves, they should always be present at the review meetings so they can say what they want for their own future and to allow them the opportunity to make decisions with support.

Some children with a rare chromosome or gene disorder will leave school at the age of 16, depending on their ability and what they want to do.

### School leaving age

Your school leaving age depends on where you live.

#### England

You can leave school on the last Friday in June if you'll be 16 by the end of the summer holidays. Until you're 18, you must then:

- ♦ stay in full-time education, e.g. at a college
- or
- ♦ start an apprenticeship or traineeship
- or
- ♦ work or volunteer (20 hours or more a week) while in part-time education or training.

#### Scotland

- ♦ If you turn 16 between 1 March and 30 September you can leave school after 31 May of that year. • If you turn 16 between 1 October and the end of February you can leave at the start of the Christmas holidays in that school year.

#### Wales

- ♦ You can leave school on the last Friday in June, as long as you'll be 16 by the end of that school year's summer holidays.

#### Northern Ireland

- ♦ If you turn 16 during the school year (1 September-1 July) you can leave school after 30 June.
- ♦ If you turn 16 between 2 July and 31 August you can't leave school until 30 June the following year.

## Post-16 Further Education (FE)

Many children with a chromosome or gene disorder go on to further education; this might be at their mainstream or special school, or elsewhere at a 6<sup>th</sup> form college, a college with a specialist unit or a residential college. Several of our diagnosed adults went on to university and some have degrees. So it is possible to learn and achieve.

- ◆ 6<sup>th</sup> form college
- ◆ College
- ◆ Residential

Your child's school and [transition support worker](#) should be able to advise on further education. You can also access a full list of residential colleges at: **Association of National Specialist Colleges** <https://natspec.org.uk/>

Some *Unique* parents compiled a list of useful questions/observations to ask on visiting a college, which you may find helpful to use:

### Things to ask about, or observations when visiting COLLEGE or similar establishments

#### COLLEGE

- ◆ Location
- ◆ Facilities
- ◆ Accreditation/inspecting body/monitoring
- ◆ Safety/security
- ◆ Size/how many students

#### APPROACH TO AUTISM

- ◆ What is the autism ethos?

#### Therapies offered

- ◆ Open minded to new approaches
- ◆ Positive approaches
- ◆ Person-centred or one-size-fits all approach

#### Challenging behaviour

- ◆ restraint procedures
- ◆ escaping
- ◆ anxiety issues

#### CURRICULUM

- ◆ Assessment of needs (ongoing, one-off)
- ◆ Independence skills, assessment/tracking/teaching methodology
- ◆ Vocational skills
- ◆ Intellectual stimulation/academic input/education
- ◆ Structure of college day

#### STAFF

- ◆ Shared vision/ethos, manifested throughout
- ◆ Friendly/warm



There are two different types of LPA's: a Property and Financial Affairs LPA and a Health and Welfare LPA

[Office of the Public Guardian](#) - The Office of the Public Guardian (OPG) protects people in England and Wales who may not have the mental capacity to make certain decisions for themselves, such as decisions about their health and finance.

[Personal Budget](#) - The disabled person's 'pot of money' to pay for their care.

[Professionals](#) - for example: teacher, social worker, doctor, paediatrician, occupational therapist, physiotherapist, speech and language therapist.

[Property and Financial Affairs LPA](#)- A Property and Financial Affairs LPA allows the donor to appoint an attorney to manage their finances and property while they still have capacity to make decisions for themselves.

[PSHE](#) - Personal, Social and Health Education. How to keep your child safe and healthy and how to interact socially.

[SRE](#) - Sexual and Relationships Education. Sex, sexuality and relationships for people with learning disabilities.

[Transition](#) - a term used nationally for the process of change for young disabled people, as they progress from childhood to adulthood.

[Transition Plan](#) - A plan drawn up from the year 9 annual review of an EHC plan. It sets out steps needed to move from school to adult life.

- ◆ transition Plan (school)
- ◆ transition Plan (paediatrician)

If you have a paediatrician, they should also be developing a plan for transfer into adult service at the hospital

[Transition support worker](#) - This is usually a person that works in the school that your child

attends, they are there to help to provide support to students and their parents and their school, to enable the most vulnerable students to make a smooth and successful transition from school to further education college, day care or residential care. Supporting students progression and transition through agreeing and implementing a plan of support.



## Glossary

This glossary will help you to understand some of the words and terms (highlighted in light blue) used in this guide.

**ADHD** - Attention Deficit Hyperactivity Disorder (ADHD) is a disorder characterised by poor concentration, which includes a combination of additional symptoms, including impulsiveness and over activity.

**Appointee** - a person approved by the DWP to act on behalf of a person receiving state benefits, but unable to manage their benefit-related affairs due to mental incapacity or severe physical disability.

**Autism** - Autism, and the related condition Asperger's Syndrome, are disorders affecting social communication. Other skills, such as interaction, language and imagination are often affected to varying degrees. A frequently used term to describe these conditions is Autism Spectrum Disorders (ASD) - and this emphasises that individuals may be affected in varying degrees and ways by these disorders.

**Bursary** - a grant awarded to someone to enable them to study in further education.

**Capacity** - able to make decisions for yourself.

**Court of Protection** - The Court of Protection makes decisions and appoints deputies to make decisions in the best interests of those who lack capacity. The Court has powers to, for example, decide whether a person has capacity to make a particular decision for themselves; and appoint deputies to make decisions for people who need help.

**Deputy** - a person - or group of people - appointed by the Court of Protection to manage the affairs of a person who has lost capacity to make decisions for themselves. Deputies are appointed when the individual in question has not granted anyone an LPA or EPA with the necessary powers.

**Deputyship** - The act of being a deputy.

**EHC plan** - A document that sets out a child's special educational needs and all the help they should get.

**Enduring Power of Attorney (EPA)** - a legal process in which a person (the donor) hands over to someone else (the attorney) the power to decide what is done with their financial affairs and property. EPA's were replaced in October 2007 by LPA's but if you made an EPA before this date don't worry because it can still be registered (with the Office of the Public Guardian).

**Lasting Power of Attorney (LPA)** - a legal document that allows a person (the donor) to choose someone that they trust (known as the attorney) to make decisions on their behalf at a time in the future when they either lack the mental capacity, or no longer wish to make those decisions themselves. It can only be used after it is registered with the Office of the Public Guardian.

- ◆ Knowledgeable
- ◆ Training
- ◆ Feedback/support
- ◆ Open-minded
- ◆ 3 E's (excitement, energy, enthusiasm)
- ◆ Staff ratios

### TRANSITION

- ◆ Transition from 16-19 and from 19+ to college (induction, open days, transitional visits etc)
- ◆ Transition from college to adult services/vocations/further training/daycare

### SOCIAL ACTIVITIES/LEISURE

- ◆ Established interests
- ◆ New interests

### ACCOMMODATION/SUPPORT

- ◆ Homely
- ◆ Living space, enough private space
- ◆ Clean, comfortable, safe
- ◆ Staff ratio for care needs (night time, waking night staff, day time)

### DIET/MEDICAL

- ◆ Special diets (including independence skills/cooking etc)
- ◆ Communication with parents re: medical issues (relationship with behaviours and medical conditions)
- ◆ Flexibility and open mindedness in meeting young person's needs
- ◆ Medical staff

### FUNDING/FUNCTION

- ◆ Experience of assisting parents obtain funding from relevant agencies
- ◆ Costs/term times/weeks of year/part-time, full-time

### DAY IN THE LIFE OF ...

- ◆ A picture of a day in the life of someone similar to my child and their needs
- ◆ Sit in on a class
- ◆ Mix of students

### FAMILY/COMMUNICATIONS

- ◆ Visits to see young person
- ◆ Communications to family
- ◆ Young person able to communicate with family i.e. Skype, messenger, phone.

When looking around, look at the clients and the staff, does everyone seem happy?

The Children and Families Act 2014 proposes an integrated approach to provision for children and young people with special educational needs and disability [SEND] across the 0-25 age range. As part of this change, funding of education and training for young people aged 16-25 in further education (FE college, 6th form college, independent specialist college) changed in 2013 to bring in a more consistent approach. Young people aged 16-25 moving from statutory schooling into non-statutory further education will be following individual programmes that centre around the young person's own aspirations, interests, strengths, capabilities and needs. It is recognised that support at college will be unique for each young person and needs will not only vary according to individual circumstances, but will change over time as young people get older and approach adult life. Further education is therefore funded on an individual needs basis to ensure successful individual outcomes. Colleges receive an allocation based on a national funding formula for their core provision. They also have additional funding for students with additional needs, including those with SEN, in their main allocation single line budget. Colleges are expected to provide appropriate, high quality SEN support using all available resources. If a college identifies that a young person aged 19-25 with an EHC plan or aged 16-19 without an EHC plan receiving education at their institution is in need of additional support, they must first explore the Local Offer (see page 13 for more information) and have been through an early help assessment (EHA). An EHA is a simple way to help identify needs of children and families and make a plan to meet those needs. It is a shared tool which can be used by all agencies in your local area, who are delivering early help. Its purpose is to provide a co-ordinated response so no-one misses out on the support they may need.

Getting financial help in England, you can apply for a 16 to 19 Bursary Fund to help with education costs.

#### **Education Maintenance Allowance (EMA)**

You may be able to claim Education Maintenance Allowance (EMA) if you're studying in Northern Ireland, Scotland or Wales. EMA is now closed in England. For more information, see:

<https://www.gov.uk/education-maintenance-allowance-ema>



Further information on the above is included in our guide entitled: Further education, training and work, which you can find on our website: <https://www.rarechromo.org/practical-guides-for-families>

#### **MENCAP** <https://www.mencap.org.uk/>

0808 808 1111 Monday to Friday 9am - 6pm

email: [helpline@mencap.org.uk](mailto:helpline@mencap.org.uk)

Information and support for people with a learning disability and their families.

#### **NATIONAL AUTISTIC SOCIETY (NAS)** <https://www.autism.org.uk/about/adult-life.aspx>

Helpline: 0808 800 4104 Mon-Thurs 10am-4pm, Friday 9am-3pm

Help with work, ageing, and managing money. You can also read real-life stories from others on the spectrum.

#### **STAY UP LATE** <https://stayuplate.org/>

01273 468168 Email: [info@stayuplate.org](mailto:info@stayuplate.org)

A charity that was set up to ensure that person-centred planning for people with learning disabilities and autism, meant that it truly reflected what an individual wanted to do in their life. In particular, they were concerned that people with learning disabilities and autism, weren't able to Stay Up Late and do the things so many people who don't need support, take for granted.

#### **THERA SUPPORT** <https://www.thera.co.uk/help/>

0300 303 1280

Thera is a group of companies that support adults with a learning disability in their own home, at work, in their local community, and for short breaks.

#### **YOUNG PEOPLES HEALTH** <http://www.youngpeopleshealth.org.uk/>

The Association for Young People's Health (AYPH) is the UK's leading charity working to improve the health and wellbeing of 10-24 year olds.

*“When the needs of the young person are identified as primarily health, then Health will provide funding to meet those needs, although this is different across the UK. There is plenty of information online about getting assessments for this and the criteria for meeting those health needs. There are some grey areas: behaviour for example, can be a health or a social issue. In Wales some young people have their needs met with 50% health/50% social funding, but the system is very different in England.”*

...guide are 'Transition matters', 'Growing up matters', 'Supporting Independence Matters', 'Sexually concerning behaviours matter', 'Work experience and employment matters', 'Deprivation of Liberty Safeguards', 'Mental capacity act matters' and many more.

#### **DISABILITY RIGHTS UK** <https://www.disabilityrightsuk.org/>

Information on disabled people's rights.

You can also purchase RADAR keys to use to open disabled toilets/ changing places via the National Key Scheme. For more information, see: <https://www.disabilityrightsuk.org/shop/official-and-only-genuine-radar-keys-key>

#### **EASY NEWS** <https://www.unitedresponse.org.uk/easy-news>

Easy News is the first news magazine designed to be accessible for people with learning disabilities.

#### **EPILEPSY ACTION** <https://www.epilepsy.org.uk/>

Advice and information on all things rated to epilepsy

#### **FAMILY CARERS** <http://www.familycarers.org.uk/>

A very useful website with up-to-date information on items like benefits changes, campaigns, news for carers, etc.

#### **IN CONTROL** <http://www.in-control.org.uk/>

In Control was set up to provide accessible information for everyone who wants to manage their own support. There are fact sheets on a range of different subjects, such as an introduction to self-directed support; how to make a support plan; organising your money; housing; jobs; opening a bank account; wills and trusts; person centred planning plus, etc.

#### **INDEPENDENT LIVING** <https://www.independentliving.co.uk/>

Independent Living – the place for impartial information about products and services to help with mobility and independence. Lots of guides on buying the right product for your needs.

#### **LEARNING DISABILITY ENGLAND**

<https://www.learningdisabilityengland.org.uk/>

0300 1110444 Email: [info@LDEngland.org.uk](mailto:info@LDEngland.org.uk)

A membership organisation for people with learning disabilities, families, friends, providers, commissioners, academics, lawyers, professionals, national and regional learning disability organisations, self-advocacy, carer, development and training organisations.

#### **LEARNING DISABILITY TODAY**

<https://www.learningdisabilitytoday.co.uk/>

Disability news and events.

## 16-19 Bursary Fund

If you're aged between 16 and 19 years and think you might struggle with the costs of education or training you may be eligible for a **bursary**. It is a grant that does not need to be paid back.

The 16 to 19 Bursary Fund provides financial support to help students overcome specific financial barriers to participation so they can remain in education.

There are 2 types of 16 to 19 bursaries:

- ◆ bursaries for defined vulnerable groups of up to £1,200 a year
- ◆ discretionary bursaries which institutions award to meet individual needs, for example, help with the cost of transport, meals, books and equipment

### Key points for the 2019 to 2020 academic year

The Department for Education (DfE) made additional bursary funding available to institutions delivering industry placements in the 2018 to 2019 academic year. DfE will also be providing additional funding in the 2019 to 2020 academic year. This funding helps ensure institutions are able to meet potential increased demand from students who may need to travel further to access their placement and/or incur additional participation costs, such as for equipment or clothing. Institutions must ensure the additional bursary funding is used in line with the 16 to 19 Bursary Fund rules set out in this guide and not guidance related to CDF.

Institutions must ensure they assess the needs of individual students when awarding bursary funding. ESFA audit and assurance work and ongoing monitoring/feedback activity by DfE has found a considerable number of institutions are making flat rate payments to students without any consideration of individual student needs. The bursary fund is designed to help students overcome the individual financial barriers to participation that they face and ensure the funds go to those who genuinely need them.

For more information on eligibility please visit:

<https://www.gov.uk/guidance/16-to-19-bursary-fund-guide-2019-to-2020-academic-year>

Your college head teacher or tutor can help you decide if you're eligible for a bursary and explain how to apply. If you have a question they can't answer you can contact the Education and Skills Funding Agency (EFA), or they might do this for you. <https://www.gov.uk/government/organisations/education-and-skills-funding-agency>

### Post -16 transport

If your child is over 16 and in further education or sixth form, your local council may be able to help with transport costs. Each council has its own policy on transport, so please visit your county council website to find out more.



## Where can I find out more about transition and organisations that provide support and information?

More work has been done in many counties on transition and many local parents have been involved in the writing of guides, so you might find that there is a guide specific to your county. You can usually find a link to this on your local county council website or local parent support organisation.

### Bridging the Gap

<https://www.rnib.org.uk/young-people-school-life-and-planning-ahead-making-transition-school/transition-guide-bridging-gap>

Transition guides from the Royal National Institute for the Blind, covering England, Wales, Scotland and Northern Ireland.

**Cerebra** <https://cerebra.org.uk/download/factsheet-transition-to-adulthood-in-england/>

Transition to Adulthood: A Guide for Parents.



### Contact - guides to preparing for adulthood

- ◆ England and Wales <https://contact.org.uk/advice-and-support/social-care/moving-into-adult-services/>
- ◆ Northern Ireland [https://contact.org.uk/media/597218/ni\\_transition\\_currentlastupdatedsep12.pdf](https://contact.org.uk/media/597218/ni_transition_currentlastupdatedsep12.pdf)
- ◆ Scotland [https://contact.org.uk/media/379959/transitionscot\\_web\\_amended\\_11\\_feb\\_2014.pdf](https://contact.org.uk/media/379959/transitionscot_web_amended_11_feb_2014.pdf)

*“ I don't know how I would have managed all these years without respite care; my son started getting respite at the age of three. It was difficult to find the right facility for him once he reached adulthood (18) but we did find somewhere out of county, which he has been going to for three years now and enjoys it. ”*

## Learning to drive

Having a disability or a medical condition does not necessarily mean you can't learn to drive. However, there are some medical conditions and disabilities that you must let the Driver and Vehicle Licensing Agency know about. You can normally learn to drive when you are 17. If you get the enhanced rate of the mobility component of Personal Independence Payment (PIP) you can learn to drive at the age of 16. All new drivers should have professional driving lessons. As a disabled driver, you may prefer an instructor who has experience of teaching disabled people.



## Links

### AMBITIOUS ABOUT AUTISM

<https://www.ambitiousaboutautism.org.uk/>

Providing services and support for young people with Autism

### CHALLENGING BEHAVIOUR FOUNDATION <https://www.challengingbehaviour.org.uk/>

For information and support contact: Family Support Line: 0300 666 0126

Email: [support@theCBF.org.uk](mailto:support@theCBF.org.uk)

A charity for people with severe learning disabilities who display behaviour described as challenging.

A charity for people with severe learning disabilities who display behaviour described as challenging.

### CHANGING PLACES TOILETS

[http://www.changing-places.org/find\\_a\\_toilet.aspx](http://www.changing-places.org/find_a_toilet.aspx)

Changing Places toilets are different to standard accessible toilets (or "disabled toilets") as they have extra features like a hoist and a changing bed that can be lowered and more space to meet the needs of people who use them.

### DIMENSIONS <https://www.dimensions-uk.org/>

Dimensions provide research-based, outcomes-focused services for people with learning disabilities and autism. Alongside supported living and residential care, they also offer vital specialist services including sector leading Positive Behaviour Support.

### DISABILITY MATTERS <https://www.disabilitymatters.org.uk/>

This is a free learning resource which is primarily designed as a teaching resource for professionals across disciplines about all aspects of disability, but there is no reason why parents can't also look at it. All modules were co-authored by parents. The relevant modules for this

....It must only be used for the disabled person's personal needs. It can't be used by the nominated driver for their own personal use. You can only have one vehicle tax exemption at any one time.

#### **How to claim**

You claim the exemption when you apply for vehicle tax.

If you're claiming for a vehicle for the first time, you have to claim at a Post Office. You must do this every time you change your vehicle.

#### **Vehicle tax reduction**

##### **Eligibility**

You can get a 50% reduction in vehicle tax if you get the PIP standard rate mobility component.

You can't get a reduction for getting the DLA lower rate mobility component.

##### **How to claim**

Send all of the following to DVLA Swansea:

- ◆ your statement of entitlement (it's at the end of your PIP award letter)
- ◆ the vehicle registration certificate (V5C)
- ◆ a V10 form
- ◆ an original MOT or GVT certificate (if your vehicle needs one)
- ◆ a cheque or payable order (made out to 'DVLA, Swansea') for 50% of the full rate of car tax for the vehicle to: DVLA, Swansea, SA99 1DZ

#### **The Motability Scheme** <https://www.motability.co.uk/about/>

0300 456 4566 8am-7pm Monday to Friday 9am-1pm Saturday

The Motability Scheme can help you with leasing a car, powered wheelchair or scooter. You'll need to be getting one of the following:

- ◆ the higher rate of the mobility component of DLA
- ◆ the enhanced rate of the mobility component of PIP
- ◆ War Pensioners' Mobility Supplement
- ◆ Armed Forces Independence Payment

VAT relief for vehicles

You may not have to pay VAT on having a vehicle adapted to suit your condition, or on the lease of a Motability vehicle - this is known as VAT relief. All Motability vehicles will be car tax exempt and the insurance will be covered in the cost, which will take all, or part of the disabled person's mobility component.

#### **Community and public transport**

Your local council may operate dial-a-ride or taxi schemes, for example, using vouchers or tokens. You may also be eligible for a bus pass, a Disabled Person's Railcard

<https://www.disabledpersons-railcard.co.uk/> or both.

#### **Council for Disabled children**

<https://councilfordisabledchildren.org.uk/>

The umbrella body for the disabled children's sector bringing together professionals, practitioners and policy-makers. It includes the former Transition Information Network.

<https://councilfordisabledchildren.org.uk/transition-information-network>

#### **Foundation for people with learning difficulties**

<https://www.mentalhealth.org.uk/learning-disabilities/a-to-zt/transition/>

A guide to transition.

#### **Lost in Transition** <https://www.dimensions-uk.org/best-practice/>

A guide to transition from Dimensions.

#### **Mencap** <https://www.mencap.org.uk/advice-and-support/children-and-young-people/education-support/transition-adult-services>

Transition into adult services guide.

#### **Person shaped support** <https://psspeople.com/>

PSS have bases in England, Scotland and Wales. Helping to provide short breaks and shared living.

#### **Preparing for Adulthood** <https://www.preparingforadulthood.org.uk/>

The Preparing for Adulthood programme (PfA) is funded by the Department for Education as part of the delivery support for the SEN and disability reforms. There are lots of very useful resources on their website.

#### **SENSE**

<https://www.sense.org.uk/get-support/information-and-advice/support-for-young-people/>

Getting a Result information pack for transition into adulthood for young people with sensory impairments and their families

## SKILL – National Bureau for Students with Disabilities

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

0800 328 5050 Email: [info@skill.org.uk](mailto:info@skill.org.uk)

◆ Northern Ireland 01232 287 000 Email: [admin@skillni.demon.co.uk](mailto:admin@skillni.demon.co.uk)

◆ Scotland 0131 475 2348 Email: [admin@skillscotland.org.uk](mailto:admin@skillscotland.org.uk)

Offering advice and information about post-16 education. Promoting equality in education, training and employment for disabled people

## Transition support group

<https://www.facebook.com/groups/transitionchild2adult/>

The 'Transition from child to adult' Facebook group is a 'private' group, which was started by the mother of a young man with a chromosome disorder, just as he was reaching 16. She wanted to talk to other like-minded parents, and couldn't find any, so she set this group up on Facebook to chat and offer support and information to other parents in the UK. Parents and professionals are welcome to join and share useful links etc.

**Parents of adult children with special needs** is its sister group

<https://www.facebook.com/groups/244661355613910/>

and for parents only, it is also a 'private' group).

## LOCAL TO YOU LINKS.....

There are many local organisations that have done a lot of work involving transition. Below is a selection of these organisations. Much of what is written on their websites might be local, but a lot of the information is relevant to any family whose child is going through transition anywhere in the UK.

## Oxfordshire Family Support Network

<http://www.oxfsn.org.uk/moving-into-adulthood/>

OxFSN has produced the "Getting a Life" series of guides to help young people and their families to plan for the future, by using person-centred thinking techniques. There are useful tips and advice on subjects that include: education, money matters, social care, finding the right support, becoming an adult, health and well-being, finding work/volunteering and somewhere to live.

**Reaching families** <http://www.reachingfamilies.org.uk/guide.htm>

'Making sense of it all' and 'Making sense of adult life' are two guides on transition for parents of young people with special needs and disabilities in West Sussex.

Some of our parents have made their own training guide using photos/pictures and text. One of our U.S. mums devised this guide for her son with regard to travelling on an aeroplane, which people could use as a guide to making their own

*"I made this e-book, "Your Plane Trip," at Tar Heel Reader a few years ago--it's probably just a place to start, but it's made for non-readers/emerging readers, and you can set it to read aloud, work the arrows with an adaptive device, etc.*



<https://tarheelreader.org/2008/11/10/your-plane-trip/>

## Blue Badge scheme

The Blue Badge scheme helps you to park closer to your destination if you're disabled. It doesn't always mean that you will get free parking; you should check the guide that comes with your blue badge and the signs in individual car parks. Some council car parks allow free parking if your car has tax exemption, but you might need to register with them first.

You can apply for a Blue Badge online if you live in:

- ◆ England or Wales <https://www.gov.uk/apply-blue-badge>
- ◆ Scotland <https://www.mygov.scot/apply-blue-badge/>
- ◆ Northern Ireland <https://www.nidirect.gov.uk/information-and-services/motoring-and-transport/blue-badge-scheme>

You will need to provide them with two passport sized photos and to pay a fee (£10) or in Scotland £20.

## Car tax exemption

You still need to apply for vehicle tax even if you don't need to pay.

### Vehicles used by a disabled person

You can claim disability exemption when you apply for vehicle tax.

### Eligibility

You can apply for exemption from paying vehicle tax if you get the:

- ◆ higher rate mobility component of Disability Living Allowance (DLA)
- ◆ enhanced rate mobility component of Personal Independence Payment (PIP)
- ◆ war pensioner's mobility supplement
- ◆ armed forces independence payment

The vehicle must be registered in the disabled person's name or their nominated driver's name.

## Libraries

Some libraries offer the following services at a reduced rate or free of charge to disabled people:

- ♦ computer access
- ♦ audio and visual material
- ♦ overdue books

Again this varies from one local authority to another. Contact your local council to find out what concessions your library offers.

Wherever you are intending to visit, whether it is a place of interest, gardens, museums, football matches, etc., always check in advance whether they offer free carer's entry, or free disabled person entry or a discount and check the accessibility, i.e. toilets/changing facilities, footpaths, car parking etc., before you travel there (so that you don't waste your journey). Some venues will require proof of disability, so you will need to take something like a doctor's letter or benefits letter and possibly some ID if you have any.

Some places specify that you need to be 'registered disabled' to qualify for discounted or free entry, but aren't clear what that means. There is no register for disabled people, so you will need proof of entitlement such as a benefit award letter and ID.

Alternatively you could show a copy of your blue badge or your disabled bus pass, although they aren't always accepted by all venues.

## Travel training

Many adults with a chromosome or gene disorder may have already learnt some travel training, if they attended a specialist school. Each local authority will have their own travel training programme and each individual will need different levels of training, so it is very much an individual thing. I have found a couple of useful resources:

**Uk Government** [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/705469/guidance.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/705469/guidance.pdf)

### South Gloucester council

<https://www.southglos.gov.uk/easyread/information-accessing-travel-transport-easy-read-format/>



**SCIE** <https://www.scie.org.uk/care-act-2014/transition-from-childhood-to-adulthood/>

The Care Act: Transition from childhood to adulthood.

### Self-directed Support in Scotland

<http://www.selfdirectedsupportscotland.org.uk/>

A one-stop shop for information about Self-directed Support for people who use social care services and health and social care professionals.

### Office of the Public Guardian in Scotland

<http://www.publicguardian-scotland.gov.uk/>

The Office of the Public Guardian in Scotland was created when the Adults with Incapacity (Scotland) Act 2000 received Royal Assent.

### The Welsh Assembly <https://gov.wales/>

0300 060 4400

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

### Local Offer <http://www.thelocaloffer.co.uk/>

Every local authority in the UK is required to publish information about available services both in and outside of their local area, for children and young people from birth to 25 years who have special educational needs and/or disabilities (SEND). Parents can access their local offer website to find out about services in their area and leisure opportunities and clubs in their area and organisations both inside and outside their local area.



*“Most charities have a guide on their website, including the transition information network, if you type in learning disability transition into a search engine, you will see lots of websites to look up. Us parents wrote the Essex guide, produced a box set of leaflets from money to housing, health and travel etc, now the council are re-writing it. Each department will also have its own transition pathway guide, i.e. health, education, social care, etc.”*

## Short breaks (respite care)

Looking after a child with a chromosome or gene disorder isn't always easy and as they get older and bigger this often becomes more difficult. Their needs might increase and we of course get older. Everyone needs a break now and again, so you shouldn't feel guilty about sending your son or daughter off for a short break, whatever age they are. Just remember it is good for them to have a break from their home and its surroundings; they meet other young people, it makes them more independent and it helps them and you to appreciate each other more. As my son has got older I always think of it as a holiday for him, as well as for me!

Your child may already be receiving respite care away from home to give your family (and your child) a break. Once they become 18 they will be classed as an adult and will have to leave children's services. So if they currently go for respite at a facility for children, that will come to an end on their 18<sup>th</sup> birthday. This should be planned for with social services (Child Disability transition team). If they were providing support and you have a care plan for your child, they should make every effort to find an appropriate, alternative respite placement in an adult facility for your son or daughter. It is important to note at this point that they will try and place your adult child in the nearest facility and it is highly likely they will have bought up several of the beds (block booking), so that they can get a better deal. Once you have visited this facility you might decide this is not the right place for your child and you must say so.

If your child is an adult and you have never tried respite care before, you must stress to the social worker that you need a break, as caring is taking its toll and in order to carry on caring at home, you need some support. In advance of your child becoming 18, I would spend as much time as you possibly can doing your own research. Respite is very difficult to come by for young adults countrywide, and it is important to remember that respite facilities will also be in a much bigger age range, 18-65 years, although there are a few places that specialise in the care of younger adults.

You can search for short term respite facilities and also residential care homes online at: <https://www.carehome.co.uk/>

I would also advise talking to other 'local' parents if you can, as some of them may already be using a respite facility that could meet your child's needs. Once your child reaches adulthood, short term respite care should be included under the assessment of need, which will be carried out by a social worker.

### SHARED LIVES

<https://www.nhs.uk/Service-Search/Shared%20lives/LocationSearch/1834>

Shared lives schemes are designed to support adults with learning disabilities, mental health problems, or other needs that make it harder for them to live on their own. The schemes match an adult who has care needs with an approved shared lives carer. These carers share their family and community life, and give care and support to the adult with care needs.

- ♦ accessibility information including disabled parking.

### CEA cinema card <https://www.ceacard.co.uk/>

023 9224 8545

The CEA card is a national card scheme developed for UK cinemas by the UK Cinema Association (UKCA), formerly the Cinema Exhibitors' Association (CEA). To apply, the person requiring assistance must be 8 years of age or older and be in receipt of one of the following:

- ♦ disability living allowance (DLA)
- ♦ attendance allowance (AA)
- ♦ personal independence payment (PIP)
- ♦ armed forces independence payment (AFIP)

Or hold:

- ♦ severely sight impaired registration (formerly Registered Blind)
- ♦ sight impaired registration (formerly Partially Sighted).

When applying for a Card please send or upload a copy of the awarding letter from DWP or a statement confirming receipt of the allowance for the applicant dated within the last 12 months.

Alternatively, for Severely Sight Impaired or Sight Impaired applicants, please send or upload a photocopy of registration for the person requiring assistance. If you are unable to find this correspondence, or do not meet the above criteria but believe that as a result of your disability you still need someone to accompany you to the cinema, please contact us. Please note they don't accept Universal Credit, Employment and Support Allowance or being a Blue Badge holder as sole proof of eligibility.

### Relaxed performances

Theatres started to offer this, on some big West End shows. Many local theatres and Cinemas are now also offering relaxed performances.

#### What is a relaxed performance?

Relaxed performances are specifically designed to welcome people who will benefit from a more relaxed performance environment, including people with an autism spectrum condition, sensory and communication disorders, or a learning disability. There is a relaxed attitude to noise and movement and some small changes made to the light and sound effects.

#### Mousetrap Theatre Projects <https://www.mousetrap.org.uk/>

33 Shaftesbury Avenue, London W1D 7EH

020 7632 4111 Email: [info@mousetrap.org.uk](mailto:info@mousetrap.org.uk)

Run many different relaxed performances during the year.

Lots of theatres offer discounted tickets for disabled people. Some also reserve seats for wheelchair users and allow carers in free. Check with the theatre when you're booking tickets to find out what they offer.

## Leisure

### Internet and how to stay safe online

The internet is a fantastic thing. You can learn so much and it can help children and adults with chromosome and gene disorders to interact with others; find out all about the world around them and just enjoy. However, for many young adults with chromosome and gene disorders who are able to use the Internet independently, or with support, it can be fraught with danger. **Keeping safe online** can be something that often many of them don't think about.

Here are some links to keeping safe online:

- ◆ Childline <https://www.childline.org.uk/info-advice/bullying-abuse-safety/online-mobile-safety/staying-safe-online/>
- ◆ Kidscape <https://www.kidscape.org.uk/advice/advice-for-parents-and-carers/internet-safety-and-online-risk/?gclid=CKj01r3Cnc4CFfQy0wod6-kGxQ>
- ◆ Mencap <https://www.mencap.org.uk/about-us/our-projects/safesurfing>
- ◆ UK Government <https://www.getsafeonline.org/>
- ◆ US website: <https://everlastrecovery.com/understanding-bullying/>

### Access for everyone - National Trust

<https://www.nationaltrust.org.uk/features/access-for-everyone>

The Essential Companion card makes it simple to bring one or two carers or companions with you, free of charge. Just show the card when you arrive, and your carer(s) or companion(s) won't need to pay an entry fee. It's in your name so you can bring whomever you like, but even if you don't have an Essential Companion card, you can still bring carers or companions free – the card just makes it quicker and simpler for you. To request an essential companion card, please either email:

[enquiries@nationaltrust.org.uk](mailto:enquiries@nationaltrust.org.uk) or phone 0344 800 1895

Most properties have a good degree of access. Unless otherwise mentioned in the relevant property information, all properties have adapted toilets. Many properties provide manual wheelchairs for loan. Self-drive and volunteer-driven powered mobility vehicles are available at larger gardens and parks.

### The rough guide to accessible Britain

<https://www.motability.co.uk/news/rough-guide-to-accessible-britain/>

The Rough Guide to Accessible Britain, produced in association with Motability Operations Ltd, is all about enjoying great days out. A free, online guide including:

- ◆ over 200 inspiring ideas for worry-free days out
- ◆ reviews, hints and tips by disabled visitors
- ◆ grouped by 10 regional locations – featuring great days out, scenic drives and towns

....Shared lives schemes are available across the country and are an alternative to traditional kinds of care, such as care homes. The schemes are sometimes also known as adult placement schemes. Before support starts, you and your child will get to know the shared lives carer and decide whether you want to spend time together.

**HFT** <https://www.hft.org.uk/>

0117 906 1700 email: [familycarersupport@hft.org.uk](mailto:familycarersupport@hft.org.uk)

Hft is a national charity providing services for people with learning disabilities throughout England. They support people to live life the way they choose - whether providing support for just a couple of hours a week, or 24 hours a day. Services include Supported Living, Residential Care and Short Break services. They have lots of very useful information on their website and provide a family carer support service. HFT also run a variety of workshops in different locations in England.

## Personal budgets and Direct Payments

**Personal budgets** are often offered by way of a direct payment into a specific bank account (usually you will set up separately from your own personal bank account), by your local county council. It will give you flexibility over how your child's care and support is arranged and provided. Direct payments are given to both people with care and support needs, and also to carers. A personal budget or direct payment will be created after an assessment by social services. If the council decides that your child needs any kind of support, they will receive a personal budget and can choose a direct payment instead of letting them arrange services for your child. If they aren't able to, or don't want to manage their own finances, it's possible for another person to manage the direct payments on their behalf. Some councils can also do this for you.

Direct payments are voluntary and you need to request or agree to have them. You can't be forced to have direct payments. If you do decide to have direct payments, you can change your mind about this at any time. If you no longer want direct payments, contact your local social services and ask them to arrange services for your son or daughter instead.

If a person lacks capacity to request a direct payment, an "authorised person" can request a direct payment and manage it on their behalf. If someone is assessed as being eligible for support and it's not possible for them to get direct payments, or they do not want one, social services must provide care and support directly, or through an individual service fund.

**Direct payments can only be spent on things that will meet the assessed needs of the person. If you spend a direct payment on something that doesn't meet your needs, social services can recover the money from you or terminate the direct payment.**

Everyone who gets support from social services should have their care and support plan reviewed at least once a year (this doesn't always happen). If someone's needs have changed, they should contact social services

.....to request a review of their care plan. If needs have changed in a way that affects the details within the current plan, the council may conduct another assessment of needs, or a financial assessment.

### **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 Disclosure and Barring Service [DBS] check and things like employer insurance and items needed in the home such as a first aid kit and fire blanket (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 had arranged the services.

Alternatively, social services may make the payments in full and ask you to reimburse them any assessed charge. If the direct payments accrue over a period of time without being used, the finance department will ask for the money back.

### **Independent living trusts**

Independent living trusts are a way for people who don't have the capacity or ability to manage their own direct payments to get support from people close to them. You can get advice on setting up a trust from the Money Advice Service

<https://www.moneyadviceservice.org.uk/en>

### **Personal budgets: Fairer Contributions policy**

An officer from the Financial Assessment and Benefits team will come out and see you at your home at a mutually agreed time. They will carry out a financial assessment to work out what your contribution will be. They will:

- ◆ agree levels of income and expenditure
- ◆ provide welfare benefits advice and make sure you are receiving all the benefits you are entitled to
- ◆ advise you of your Fairer Contribution and confirm this in writing

### **When will I have to start making contributions?**

If you (as a parent) have been financially assessed to make a contribution towards your child's care, this will be payable from the day they start to receive care.

### **Continuing health funding**

Continuing healthcare funding, also known as CHC funding, is a package of health and social care funding provided to meet the cost of an individual's care in full because their primary need for care is a health need. It is not means tested.

## **Grants for young adults with disabilities**

Lawrence Atwell's Charity

<https://www.skinners.org.uk/grants-and-trusts/atwell/individuals/>

020 7213 0561 Monday to Friday between 9am-5pm

Email: [atwell@skinners.org.uk](mailto:atwell@skinners.org.uk)

Grants are available for young people living in England and Wales from low-income backgrounds, to help them gain vocational, accredited qualifications. They offer grants of up to £1,500 for people aged 16 to 26, to take courses (up to level 3) that will help them move into employment. Funding can be given for course fees, equipment/materials, travel costs, childcare and living costs.

### **The Prince's Trust Development Awards**

<https://www.princes-trust.org.uk/help-for-young-people/get-funding-train-learn>

To speak to an advisor call free: 0800 842 842

Development Awards can help to cover costs such as: course fees, transport or equipment to help your child achieve their plan to get into education, training or employment.

### **Who can apply?**

Your child may be eligible if you are a UK resident and are:

Aged 14-17, and do not have/are not expecting to achieve 5 GCSEs grades A-C (or equivalent), or

Aged 17-25 and unemployed or working fewer than 16 hours a week, or in education fewer than 14 hours a week

Be aware that there are criteria of how the money can and can't be spent. Here are some examples:

Development Awards can be used to help fund:

- ◆ tools or equipment for a job or qualification e.g. hairdressing kit, carpentry tools, chef whites
- ◆ course fees
- ◆ interview clothes
- ◆ license fees e.g. CSCS card (construction) or SIA license (security)
- ◆ Childcare costs to help single parents access short term education
- ◆ transport to a new job until first pay cheque.

**Turn 2 Us** <https://grants-search.turn2us.org.uk/>

Turn2us is a national charity that helps people gain access to welfare benefits, charitable grants and support services.

### **Disability Grants**

<https://www.disability-grants.org/grants-for-disabled-young-adults.html#sthash.CzBV1CIN.dpuf>

This website provides links to charities that you can apply to for Funding.

### **The Brook Advisory Centre** <https://www.brook.org.uk/>

Free and confidential sexual health advice and services specifically for young people under 25.

### **CHANGE** <https://www.changepeople.org/shop/products>

As a result of the ground-breaking research CHANGE did in partnership with the University of Leeds, they have produced 5 books in easy read about 'Sex and Relationships' for people with learning disabilities.

### **DVD**

#### **Life Support Productions** <https://lifesupportproductions.co.uk/>

Produce DVD's to aid in the teaching of SRE/PHSE

## **Books and DVD's**

### **Bag books** <http://www.bagbooks.org/>

A UK-wide charity making multi-sensory books for children and adults with Severe Learning or Profound and Multiple Learning Disabilities

### **Beyond Words** <https://booksbeyondwords.co.uk/>

020 8877 9799

Email: [admin@booksbeyondwords.co.uk](mailto:admin@booksbeyondwords.co.uk)

Beyond Words is a provider of books, services and training for people who find pictures easier to understand than words. Whether supporting somebody with a learning disability or communication difficulty, our products and services empower through pictures.

### **Safe and Secure**

<https://www.thera.co.uk/projects/safe-and-secure/>

0300 303 1280

Email: [info@thera.co.uk](mailto:info@thera.co.uk)

Many families are worried about what will happen in the future when they are no longer able to care for their relative with a learning disability. Safe and Secure England is a book published by Thera Trust. It will empower people and their families to make decisions about the future and overcome their fears. The book is available free, but a donation to cover the cost of p&p is required.



## **Benefit information and advice**

When a young person turns 16 they are expected to take on responsibility for any benefits they claim in their own right. But if they are unable to manage their own affairs you can become their 'appointee' for benefit claims.

### **What is an appointee?**

If you are made an appointee for your child's benefits this means you are responsible for making any claims, giving any information required and telling the Department of Work and Pensions (DWP) of any changes that may affect their entitlement to benefits.

### **How do I become an appointee?**

Contact the DWP who will arrange a home visit. This is usually a straightforward process and should not delay any claims that you are making.

### **Contact benefits helpline**

<https://contact.org.uk/advice-and-support/benefits-financial-help/benefits-and-tax-credits/benefits-at-16/>

0808 808 3555

Email: [helpline@cafamily.org.uk](mailto:helpline@cafamily.org.uk)

### **Help with filling in forms, tips and appealing decisions**

- ◆ Benefits and Work: <https://www.benefitsandwork.co.uk/>
- ◆ Entitled To: <https://www.entitledto.co.uk/default.aspx> Handy benefits calculator
- ◆ Disability Rights UK: <https://www.disabilityrightsuk.org/personal-independence-payment-pip> DRUK have two guides to claiming PIP on their website, one of which is an easy read guide.
- ◆ Turn to us: <https://www.adviceuk.org.uk/turn2us-benefits-calculator/>

### **DWP helplines**

#### **Carer's Allowance Unit**

0800 731 0297 Monday to Friday, 8am to 6pm

The Carer's Allowance Unit provides information regarding Carer's Allowance and Carer's Credit.

#### **Employment and Support Allowance (ESA) from age 16:**

<https://www.gov.uk/employment-support-allowance>

If you're ill or disabled, Employment and Support Allowance (ESA) offers you:

- ◆ financial support if you're unable to work
  - ◆ personalised help so that you can work if you're able to.
- You can apply for ESA if you're employed, self-employed or unemployed. You might be transferred to ESA if you've been claiming other benefits like Income Support or Incapacity Benefit.

## Work Capability Assessment

You must have a Work Capability Assessment while your ESA claim is being assessed. This is to see to what extent your illness or disability affects your ability to work.

You'll then be placed in one of 2 groups if you're entitled to ESA:

- ◆ work-related activity group, where you'll have regular interviews with an adviser
- ◆ support group, where you don't have interviews

### What you'll get

How much ESA you get depends on:

- ◆ your circumstances, e.g. income
- ◆ the type of ESA you qualify for
- ◆ where you are in the assessment process

## Personal independence payment (PIP) <https://www.gov.uk/pip>

Freephone 0800 917 2222

Personal Independence Payment (PIP) is a benefit that replaced Disability Living Allowance (DLA) for adults aged between 16-64. DLA will continue as a separate benefit for children aged under 16 years. Children turning 16 who currently claim DLA will be asked to claim PIP after their 16th birthday. This applies to all children turning 16 no matter where in England, Wales or Scotland they live. Young people turning 16 who get DLA under the special rules for the terminally ill are exempt and will continue to get DLA. The Department of Work and Pensions (DWP) will write to you when your child is 15 years and 7 months. They will explain what will happen and check whether your child has the mental capacity to deal with their own benefit claims or whether they will need an appointee to act on their behalf. Their DLA payments will continue until a decision is made on their PIP claim. This applies even if their existing DLA award was scheduled to end when they turned 16. However, if they fail to claim PIP when invited, their DLA payments will stop. Apart from young people turning 16, three other groups are invited to claim PIP regardless of where in the country they live. These are DLA claimants who are:

- ◆ aged 16 or above and who report a change in their care or mobility needs
- ◆ aged 16 or above and who volunteer to claim PIP
- ◆ already aged 16 or above and whose existing DLA award is coming to an end.

## Qualifying for Personal Independence Payment

Like DLA, PIP is made up of two parts. There is a mobility component based on your ability to get around and a daily living component based on your ability to carry out key activities necessary to participate in daily life. Depending on their circumstances a person might qualify for one or both. In addition:

- ◆ it is not means tested or based on National Insurance contributions
- ◆ it can be paid to both those in and out of work

## SRE (Sexual and Relationships Education) and PSHE (Personal, Social and Health Education)

Talking about subjects of a delicate or intimate nature with your child can be uncomfortable for any parent, and it can be even harder if your son/daughter has learning disabilities. It is important to communicate openly about these issues, so that your son/daughter develops the confidence to talk about them and knows it's okay to do so, rather than 'bottling it up' and getting anxious. In the long term, this will help them to talk to the right people and keep safe if there comes a time when you are no longer around to support them. For some young adults with a chromosome or gene disorder, it is important to get advice on this subject.

Advice on sexual health should be available through your local GP or clinic. It is also worth contacting a local family planning service as they have resources available for adults with learning disabilities: **FPA online:** <http://www.fpa.org.uk/sex-and-disability>

## Foundation for people with learning difficulties

<https://www.mentalhealth.org.uk/learning-disabilities/our-work/family-friends-community/thinking-ahead/section-4-talking-about-difficult-subjects/>

Resources including a guide on 'Talking about difficult subjects'.

## Oak Field School & Sports College, Nottingham.

email Matthew Riley: [careerslead@oakfield.nottingham.sch.uk](mailto:careerslead@oakfield.nottingham.sch.uk)

Oak Field School in Nottingham, staff, parents and students have worked over many years to address this area of education. The school produces many resources for students and their families, including Living Your Life which was written by the school and published by Brook and has other publications available to purchase for a small cost:

<http://www.oakfieldsportscollege.org.uk/uploads/SRE-BookletOrderForm.pdf>

David S Stewart OBE DL was the Head Teacher of Oak Field School where he has taught for over 30 years until his retirement in 2019. For over 25 years the school has built a reputation for work in this area of education and children and young people with special educational needs. He lead training around the country with schools, parents and families. David Stewart and his students have spoken at two past Unique conferences and we are very grateful for his support.

- ◆ Irene Tuffrey-Wijne has done a lot of work in the area of how to break bad news to people with learning difficulties: <http://www.breakingbadnews.org/> and has written books on the subject of bereavement, which are available here: <https://www.jkp.com/uk/how-to-break-bad-news-to-people-with-intellectual-disabilities-2.html/>
- ◆ Beyond Words <https://booksbeyondwords.co.uk/> 020 8877 9799 Email: [admin@booksbeyondwords.co.uk](mailto:admin@booksbeyondwords.co.uk) Have produced a series of picture books that make communicating easier for people with learning disabilities, including:
  - ◆ am I going to die?
  - ◆ when Dad died
  - ◆ when Mum died
  - ◆ when somebody dies
- ◆ Who Will Care After I'm Gone? <https://www.fitzroy.org/wp-content/uploads/Who-will-care-after-im-gone.pdf> A report looking at the pressures faced by parents/carers of people with learning disabilities.

## Wills and Trusts

When my husband and I wrote our wills, we set up a discretionary disabled trust for our son. He has named trustees who can access his money (when we pass), to buy him things he needs in the future e.g. clothes, TV, furniture, holidays etc. We set this up with our solicitor who understood our needs. There are organisations that can help with information.

**Mencap** have a Wills and Trusts service and a booklet, which can be accessed here: <https://www.mencap.org.uk/advice-and-support/wills-and-trusts-service> They also run free 'planning for the future' seminars all over the country, delivered by a local solicitor. For more information please visit the website, call 0207 696 6925 or email: [willsandtrusts@mencap.org.uk](mailto:willsandtrusts@mencap.org.uk)



- ◆ there are special rules for the terminally ill
- ◆ those getting the enhanced rate of the mobility component of PIP can make use of the Motability scheme (see links pages for more information)
- ◆ an award of the daily living component can lead to a carer getting Carer's Allowance.

**Jobcentre Plus** <https://www.gov.uk/contact-jobcentre-plus>

0345 604 3719 Hours: Monday to Friday: 9.00 am to 5.00 pm  
A national number to find out more about the support available for people wanting to return to work.

**NB:** This information was correct at time of publication. Please check the UK Government website for updates, as the benefits system updates in April each year.

## Person-centred planning

Person-centred planning (PCP) is designed to help a person plan their life and their support. It is used most often to enable individuals with disabilities or those requiring support to increase their personal independence. Information on PCP can be found on the following websites:

**Helen Sanderson Associates** <http://helensandersonassociates.co.uk/> 0161 442 8271 email: [info@helensandersonassociates.co.uk](mailto:info@helensandersonassociates.co.uk)

Provide training and consultancy for families, for people who want to develop their own person-centred plans, and for organisations.

**Circles Network** <https://circlesnetwork.org.uk/>

01788 816671 Email: [info@circlesnetwork.org.uk](mailto:info@circlesnetwork.org.uk)

Circles Network exists to complement the efforts of people at risk of exclusion to become the architects of their own lives by:

- ◆ engaging in all aspects of community life
- ◆ increasing confidence, respect and value
- ◆ fostering a variety of interdependent relationships
- ◆ encouraging informed choice and individual happiness

**Circles Network** <https://circlesnetwork.org.uk/>

01788 816671

Email: [info@circlesnetwork.org.uk](mailto:info@circlesnetwork.org.uk)

Circles Network exists to complement the efforts of people at risk of exclusion to become the architects of their own lives by:

- ◆ engaging in all aspects of community life
- ◆ increasing confidence, respect and value
- ◆ fostering a variety of interdependent relationships
- ◆ encouraging informed choice and individual happiness
- ◆ improving personal wellbeing, safety and happiness
- ◆ developing gifts and competencies towards productive, fulfilling lives.

## ADVOCACY

**National Youth Advocacy Service** <https://www.nyas.net/>

Freephone helpline: 0808 808 1001

Helpline is open 9am - 8pm Monday to Friday 10am until 4pm Saturdays

Email: [help@nyas.net](mailto:help@nyas.net)

The Helpline provides a free single point of access to all NYAS services. Advisers support children, young people and vulnerable adults across England and Wales to ensure their rights are upheld. They welcome enquiries from representatives of children, young people, and vulnerable adults such as professionals, practitioners, family or friends.

**VOICEABILITY** <https://www.voiceability.org/>

Easy Read version: <https://www.voiceability.org/easy-read>

01223 555800 opening hours are 9am to 5pm, Monday to Friday, (closed between 1pm - 2pm).

VoiceAbility supports people who face disadvantage or discrimination, to have a voice that counts.



*“Maybe contact an advocacy organisation that deals with disability. They are a really great source of information about what’s out there for our young adults. They can help with writing a person centred plan (PCP) for your young adult (irrespective of them being verbal or non-verbal). This helps them to get what they really want to do and provides a statement of their goals in life.”*



## Bereavement

Death is never an easy subject to talk about, especially in regard to our children. However, for some Unique parents it might be something that has to be faced. When the time comes it is difficult, so I wanted to include some information to help.

I have looked into getting an insurance policy for my son but couldn't find anyone willing to insure him. I am sure there must be something, but as yet I haven't found it. So you could create a savings account (in your name) just for that purpose, should you ever have to face the unthinkable.

The UK government can help with funeral expenses if you are on a low income. They can only give you money towards the funeral, it wouldn't cover the full cost and if the deceased had savings, the government can claim back from the deceased's estate. For more information, see: <https://www.gov.uk/funeral-payments> or contact your Jobcentre Plus and ask for form SF200.

The other way to pay for the cost of a funeral would be to take out a funeral plan. Many companies advertise these online, mostly for people over 50. Some companies might advise that you need to arrange a funeral plan at branch level, if the person to be insured is under 50, so you will need to go into your local funeral directors to discuss your options.

Links that may help overcome grief for parents:

- ♦ personal stories to read online: <https://www.careforthefamily.org.uk/family-life/bereavement-support/bereaved-parent-support>
- ♦ the Compassionate Friends <https://www.tcf.org.uk/>

### Loss of a relative

My learning disabled non-verbal son absolutely adored his grandad, so when he died (several years ago), I had no idea how I was going to explain this to my son. He had little understanding and although I told him that his grandad was very sick and had gone to sleep and wouldn't wake up, I don't think he understood at all and it was a very difficult time for me as well. I searched for resources at the time and found very little available. The charity Child Bereavement UK suggested I make up a memory box with photos and things that were my dad's to put inside. I did this, but found it too painful to bring it out to show my son and I don't think he knew what it was all about anyway. Work has been done on giving people with learning disabilities bad news, since my dad passed away. There are a few online resources which may help:

- ♦ Child Bereavement UK  
0800 02 888 40  
<https://www.childbereavementuk.org/>
- ♦ Foundation for People with Learning disabilities <https://www.mentalhealth.org.uk/learning-disabilities/a-to-z/b/bereavement>
- ♦ The British Institute for Learning Difficulties <http://www.bild.org.uk/resources/factsheets/>
- ♦ An easy read guide from Easy health <http://www.easyhealth.org.uk/>

## What happens when you go into hospital <http://www.easyhealth.org.uk/>

A guide in large easy to understand words and pictures.

Most NHS treatment is free, but there are a number of things for which there may be charges. This information tells you what you might be able to get help with, and whether your child might be entitled.

### Health costs for which you can get help

For a full list of entitlement, see form HC1:

<https://assets.nhs.uk/prod/documents/HC1-September-2018.pdf>

If you qualify they may be able to get help with:-

- ◆ prescription charges
- ◆ NHS dental charges, including check-ups
- ◆ sight tests
- ◆ vouchers towards the cost of glasses and contact lenses
- ◆ travel costs to and from hospital for NHS treatment.

They will need to show evidence to prove that they are eligible for help.

## Mental Health Services

**CAMHS** (Child and Adolescent Mental Health Services)

<https://youngminds.org.uk/find-help/your-guide-to-support/guide-to-camhs/>

Your child may be referred to CAMHS because of **ADHD**, anxiety, autism, behavioural issues, depression, or other mental health issues. Child and adolescent mental health disorders are surprisingly common. There will be a service covering your area. When your child becomes an adult, there should be a transition from CAMHS to Adult Mental Health Services (AMHS). However, this varies around the country, as does the age of transition, which is aged 16 for some and aged 18 for others. To get any service from AMHS, the severity of illness is higher than the criteria for accessing CAMHS; so many young people don't get any service at all.

There is campaigning going on to improve mental health services for both children and adults.

Young Minds <https://youngminds.org.uk/> have done a lot of work in this area and have lots of resources on their website.

### Social Care Institute for Excellence (SCIE)

<https://www.scie.org.uk/children/transition>

020 7766 7400 Email: [info@scie.org.uk](mailto:info@scie.org.uk)

UK resource of good practice and knowledge aimed at improvement of social care services with focus on central role of people who use services. Supports effective transitions in mental health services for young adults. SCIE's work on mental health service transition aims to improve the experience of young people who are moving from mental health services for children and adolescents to adult mental health services or alternative support in adulthood. There are lots of transition resources at:

<https://www.scie.org.uk/care-act-2014/transition-from-childhood-to-adulthood/>

## Personal Communication passports

For many young people with chromosome or gene disorders, trying to communicate with others can be difficult. Whether they are verbal or non-verbal, it can be very difficult to explain how they are feeling, what they like, what they dislike, etc. A communication passport is a way of helping them to express their likes and dislikes to others. Usually a passport consists of pictures and words. These can be very useful in communicating with service providers.

You can download templates to create your own from:

**My Communication Passport** <http://www.mycommpass.com/>

**Easy health** <http://www.easyhealth.org.uk/>

Email: [easyhealth@generate-uk.org](mailto:easyhealth@generate-uk.org) 020 8879 6333.

Communication passports for going into hospital.

*“Make sure you have a good idea of what you would like for your young person - college/support/respice. Have a look out there to see what is available and be open to other suggestions.”*



*“Like all things in life, the move into adulthood is a gradual transition but it creeps up quickly! You need to be prepared. One article I read said it was like "jumping into an abyss" and "hurtling into a void" and it is. No one does it for you, so go to as many seminars, read as much information and talk to as many other parents/ carers who have experienced this as you can to support your journey.”*

## Banking

Banking for a young adult with a chromosome or gene disorder can be complicated. Banks can have very different advice. I tried to get a bank account for my son, who has no capacity at all and they wouldn't allow it because he needs to be able to sign and to know why he is signing. In the end I set up a bank account in my name only (as suggested by social services) to take his direct payments. I buy him everything he needs. It is very personal to us and I know that not everyone does things the same and all individuals have differing needs and different ways of doing things; that is why it is important to get advice from as many sources as possible. For young adults with a chromosome or gene disorder, who have a mild to moderate learning disability; getting your head around money and spending it can be a long process. Many of them will have learnt how to understand money and shopping in school, while many will still have problems using money and will always need some assistance. The British Institute for Learning Disabilities in conjunction with Barclays Bank have produced an easy read guide on banking and money skills: <http://www.bild.org.uk/about-bild/ourwork/money-skills/>

**Dosh** <https://www.dosh.org/>  
0300 303 1288 Email: [info@dosh.org](mailto:info@dosh.org)

Dosh has a series of factsheets for carers who manage their son or daughter's money. They have worked with family carers to find out what information they need to help them and written these factsheets based on this work. Their factsheets cover information on:

- ◆ appointeeship
- ◆ benefits
- ◆ checklist for financial health
- ◆ making banking easier
- ◆ mental capacity
- ◆ planning for the future
- ◆ top tips for managing family money
- ◆ where does the money come from (infographic)

These are available to download for free from:  
<https://www.dosh.org/learn-about-money/factsheets-for-family-carers/>

### Money advice service

<https://www.moneyadvice.service.org.uk/en/categories/care-and-disability>  
and <https://www.moneyadvice.service.org.uk/en/articles/money-saving-tips-and-discounts-for-disabled-people>

0800 138 7777 Monday to Friday, 8am to 6pm

Free and impartial money advice. They also have a guide called *'Helping young people with learning disabilities to understand money.'*



## GOING INTO HOSPITAL

### Adult learning disabilities liaison nurse

Check if the hospital your adult child is attending, has a learning disability liaison nurse. If the person you care for is being referred to hospital by their GP, you can ask the GP to check whether the hospital has a learning disability liaison nurse. This is a specialist nurse who supports adults with a learning disability while they are in hospital, to make sure they get the care they need. It may be possible to choose to go to a hospital that has this service. It's important that the nurse meets the person with a learning disability as soon as possible after they arrive at hospital. This is so the nurse can find out as much helpful information about the patient's learning disability and their preferences, and to understand the help they may need while in hospital. It may be possible to arrange a meeting before the hospital stay e.g. best interests decisions are often made with more than one professional attending an outpatient appointment.

Let the hospital know about their chromosome or gene disorder/ learning disability/autism in advance if possible. Before going into hospital, make sure the hospital staff are aware of the type of disability the patient has. This should be something the GP includes in their referral letter – but ask them about this to make sure. You can create a hospital communication passport to help explain your son or daughter's needs, likes, and dislikes (most hospital websites will have a copy that you can download and fill in). If it is an unplanned visit, you should ask if the hospital has an adult learning disabilities liaison nurse on arrival, if your son or daughter is to become an inpatient.

### Carer's support service

Many hospitals have a carers' support worker based in the hospital. If you are staying with your adult child in hospital and the nurses on the ward don't suggest it, ask them if they could contact the carers' support worker in the hospital and ask them to come and visit you on the ward.

*“ My son broke his elbow very badly and required surgery. He was on the trauma ward for a week and the staff from beginning to end were amazing with him (I had filled in a hospital passport at their request). They called the carers' support worker in the hospital, who came to see us a day or so after my son had surgery, to check that we (my husband and I) were OK and whether we needed anything. It made a big difference to talk to someone who wasn't a medical professional or a family member.”*

The Annual Health Check should allow the person with learning disabilities go to their GP practice and have aspects of their health checked. It also allows them to talk about anything that is worrying them. During the health check, the GP or practice nurse should carry out the following for the patient:

- ◆ a general physical examination, including checking their weight, heart rate, blood pressure and taking blood and urine samples
- ◆ assessing the patient's behaviour, including asking questions about their lifestyle, and mental health
- ◆ a check for epilepsy
- ◆ a check on any prescribed medicines the patient is currently taking
- ◆ a check on whether any chronic illnesses, such as asthma or diabetes, are being well managed
- ◆ a review of any arrangements with other health professionals, such as physiotherapists or speech therapists.

The GP or practice nurse should also provide the patient with any relevant health information, such as advice on healthy eating, exercise, contraception or stop smoking support.

People with learning disabilities have lots of different needs. Sometimes these are written down in a health profile or health action plan that the GP or nurse can refer to. Putting "reasonable adjustments" in place can help people to have a successful health check. Reasonable adjustments means changing services so that they are easier to use. These adjustments can include:

- ◆ using pictures, large print, and straightforward language to help explain what is happening
- ◆ booking longer appointments
- ◆ scheduling an appointment that starts at the beginning or end of the day, so people don't have to wait.



All parts of the health check are voluntary. Anyone who is having the health check, or their carer, can ask the GP or practice nurse for more information about the process. The patient can then give their consent before any tests or procedures are carried out.

### EASY READ HEALTH GUIDES

There are some really helpful easy to read guides on a variety of health problems on the Foundation for Learning Disabilities website: <https://www.mentalhealth.org.uk/learning-disabilities/our-work/health-well-being/easy-read-guides-health-conditions/>

## Housing

When your child becomes an adult, they have the right to decide where they want to live. Some options include:

- ◆ continuing to live at home with their parents or carers
- ◆ living with a shared lives carer
- ◆ applying for sheltered housing or a flat through their council or housing association
- ◆ moving into private rental accommodation, alone, or with friends



**MY SAFE HOME** <http://www.mysafehome.info/>  
02476 402211

My Safe Home helps people with learning disabilities, mental health problems, and physical disabilities to buy their own home with shared ownership. Open to people on high or middle rate care Disability Living Allowance or the equivalent Personal Independence Payment across England and Wales, home ownership is a viable, life enhancing housing option that offers many benefits.

### COUNCIL TAX REDUCTION

Your child might be entitled to a discount on your council tax if they have to live in a larger property than they would have needed if they were not disabled. It's called the 'Disabled Band Reduction Scheme'.

For example: you build an extension on your property to create a wheelchair-accessible bathroom. This increases the size of your property and pushes your property into a higher council tax band. However, because the extension was built to create a more accessible home, you can get your council tax bill reduced, so that you pay the same as you did before the extension. Contact your local council to apply for the scheme.

This is not available in Northern Ireland; there is no council tax in Northern Ireland, which still has a rating system and a different scheme. See: <https://www.nidirect.gov.uk/information-and-services/guide-rates/help-paying-your-rates>

There is also another council tax reduction, which isn't always widely publicised. If you are the carer of a 'severely mentally impaired' (SMI) person, and you care for them for at least 35 hours a week, you may be entitled to a council tax reduction of 25%. This is a reduction in your council tax bill because someone aged 18 or over who lives with you is mentally disabled and not counted for council tax purposes. The council tax rules state that they must be 'severely mentally impaired.' Continued on the next page....

### ....The Council Tax Discount scheme

You as a carer can get a discount of 25% off your bill if you are the only person living in your home or if all the other occupiers are 'disregarded' for council tax purposes. You can get a 50% discount off your bill if you and all the other occupiers are disregarded. Those who are disregarded include:

- ◆ people who are considered to be 'severely mentally impaired';
- ◆ certain types of carer;
- ◆ people in hospital, a care home, or certain kinds of hostel; anyone whose 'sole or main residence' is elsewhere; and young people, students, student nurses, youth trainees, apprentices and certain other groups.

### DISABILITY EQUIPMENT

There should be no VAT on disability equipment or adaptations.



*“As we were approaching the time for my son, C. now aged 20 yrs., to go through the transition period from child services into adulthood, I was absolutely dreading it, as I had read so many stories of people having to fight and battle for their young people; so I was ready for battle myself when the process started. We were allocated a transition social worker, who was absolutely brilliant; she stole my thunder in a way, as I had built myself up for a fight! She was by our side every step of the way, taking C. and myself to see various day care centres and respite centres and also included C. in the decision making where applicable. Once the budget for C. had been decided, and he started using the daycare/respite services, she stayed with us for around 3 more months to make sure he/we were happy with the choices that were made. All in all, the whole transition period for us was a very pleasant one. C. no longer attends the respite centre at the moment as he had a few issues, we have also changed to a different day care centre but he is happy and settled.”*

### Access to health services

Adult health services, including therapies, work differently to paediatric services. They tend to see people to sort out specific problems for a specific length of time, rather than providing long term follow-up for many years like paediatric services may do. Depending on your son or daughter's medical needs, they may be transferred to an adult secondary care or hospital service such as learning disability psychiatry, adult neurology or adult rehabilitation when they leave paediatric care, but how long they are then followed up will depend on their condition and particular medical problems. Criteria to access these services is variable depending on your area, so you should discuss this with the paediatrician during transition. The GP should be the first point of contact after leaving school if any new health services are needed including physiotherapy and/or speech therapy services. If a person is attending social services day care provision then they might have access to health services on site. Access to equipment can be through the GP, social services, physiotherapist or occupational therapist.

### Health checks for adults with learning disabilities

<https://www.nhs.uk/conditions/learning-disabilities/annual-health-checks/>

People with learning disabilities often have poorer physical and mental health than other people. The Annual Health Check scheme is for adults and young people aged 14 or above with learning disabilities who need more health support and who may otherwise have health conditions that go undetected. People aged 14 and over who have been assessed as having moderate, severe or profound learning disabilities, or people with a mild learning disability who have other complex health needs, are entitled to a free annual health check. People with learning disabilities often have difficulty in recognising illness, communicating their needs and using health services. Research shows that regular health checks for people with learning disabilities often uncover treatable health conditions. Most of these are simple to treat and make the person feel better, while sometimes serious illnesses such as cancer are found at an early stage when they can be treated. The annual health check is also a chance for the person to get used to going to their GP practice, which reduces their fear of going at other times.

#### How do you get an Annual Health Check?

Adults and young people aged 14 or above with learning disabilities who are known to their local authority social services, and who are registered with a GP who knows their medical history, should be invited by their GP practice to come for an annual health check. However, this isn't happening in all parts of the UK.

*“I tried to get my GP surgery to do an annual health check on my adult son, but they said they didn't do them.”*

....FREE to Shared Lives Plus members.

- ◆ shared lives carer support officer 0151 227 3499
- ◆ legal advice helpline 0330 303 1876
- ◆ benefit advice helpline 0151 541 0240

Shared Lives Plus is the UK network for family-based and small-scale ways of supporting adults. Members are Shared Lives carers and workers, and Home share programmes. Shared Lives used to be known as Adult Placement.

## Health and Social care

### Continuing Health care

The GP remains 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. Paediatric health services usually keep children under their care until at least 16 years of age and often until 18 or 19 years if the young person remains in full time education. There should be a planned transition to an adult clinician.

### Health and Social Care NICE Guidelines on Transition

<https://pathways.nice.org.uk/pathways/transition-from-childrens-to-adults-services>

These guidelines cover the period before, during and after a young person moves from children's to adults' services. Parents and young people should know that they exist and that health professionals have a duty to develop a comprehensive transition and transfer plan for young people.

#### Who is it for?

- ◆ young people using health who may need support from adults' services in the future
- ◆ their parents or carers
- ◆ health and social care providers.

#### What recommendations does it make to health providers?

Transition planning should start early (11-13 years). Transition planning should be developmentally appropriate and take into account the young person's capabilities, needs and hopes for the future.

#### 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, paediatrician or school nurse. Any therapy required should have been identified in the transition plan, so that all services are aware before an individual leaves school.

## Legal information

Once your child becomes 18 and an adult in their own right, it is important to know about the legalities of being a parent to a child with a chromosome or gene disorder/learning disability. This legal stuff can be very confusing and daunting. There are a few subtle differences between England and Scotland's legal system and also depending on whether your child is to stay living with you, or moving into their own home/supported living/residential accommodation, there are different requirements. The main legalities are listed below.



### Mental Capacity Act

The Mental Capacity Act 2005 covers people in England and Wales who can't make some or all decisions for themselves. The ability to understand and make a decision when it needs to be made is called 'mental capacity'.

### Mental Capacity Act Code of Practice

<https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice>

The code of practice gives guidance to people who:

- ◆ work with people who can't make decisions for themselves
- ◆ care for people who can't make decisions for themselves

It says what you must do when you act or make decisions on behalf of people who can't act or make those decisions for themselves. The Mental Capacity Act 2005 (MCA) says certain people must think about the code of practice when they act or make decisions on the other person's behalf. This includes:

- ◆ an attorney appointed under a lasting power of attorney
- ◆ a deputy appointed by the Court of Protection
- ◆ an independent mental capacity advocate
- ◆ a person doing research approved in accordance with the MCA
- ◆ a person who acts in a professional capacity for, or in relation to, people who can't make decisions for themselves
- ◆ a person who is paid to act for or in relation to people who can't make decisions for themselves

Mencap has also produced a guide on the Mental Capacity Act, you can view it here: [https://www.mencap.org.uk/sites/default/files/2016-06/mental%20capacity%20act%20resource%20pack\\_1.pdf](https://www.mencap.org.uk/sites/default/files/2016-06/mental%20capacity%20act%20resource%20pack_1.pdf)

### Best interests' decisions

If a person has been assessed as lacking capacity, then any action taken, or any decision made for, or on behalf of that person, must be made in his or her 'best interests'. The person who has to make the decision is

.....known as the 'decision-maker', this could be the parent/carer or a medical professional e.g. a doctor.

### **What are the 'best interests'?**

Health professionals and others must act in the best interests of the person who lacks capacity before taking certain steps that affect their care and treatment. Some of the factors to take into consideration are:

- ◆ supporting their involvement in acts done for them and decisions affecting them.
- ◆ considering all the wishes, feelings or instructions they expressed before losing capacity to make the decision, as well as any beliefs and values that are important to them.
- ◆ considering the views of their carers, family, or people who may have an interest in their welfare, or people they have been appointed to act for them.

### **Deprivation of liberty safeguard (DOLS)**

A deprivation of liberty (families might hear this referred to as DOLS) is where the person who lacks capacity's liberty is taken away from them. That is, they are not free to leave and are under continuous supervision and control. The Mental Capacity Act says that the law allows this only in very specific situations. This may happen to them if they need to go into a care home or hospital to get care or treatment, but they don't have the capacity to make decisions about this themselves. A DOLS sounds quite scary, but it is essentially to safeguard their human rights and is reviewed regularly by the Local Authority and the service providers. It is also done in partnership with families.

### **Court of Protection and Deputyship**

You can apply to become someone's deputy if they 'lack mental capacity' – meaning that they can't make a decision for themselves at the time it needs to be made. They may still be able to make decisions for themselves at certain times.

As a deputy, you'll be authorised by the Court of Protection to make decisions on their behalf. There are 2 types of deputy:

- ◆ property and financial affairs, e.g. paying bills, organising a pension
- ◆ personal welfare, e.g. making decisions about medical treatment and how someone is looked after.

You can apply to be just one type of deputy or both. If you're appointed, you'll get a court order stating what you can and can't do.

### **How to apply**

Check you meet the requirements to be a deputy. Send the application forms to the Court of Protection and pay the application fee. You don't need to be a deputy if you're just looking after someone's benefits. Apply to become an appointee instead.

### **Checks on your application**

The Court of Protection will check:

- ◆ whether the person needs a deputy, or some other kind of help

## **Care providers**

### **Care at home**

If your child needs care at home, you can find and compare all homecare services near you on NHS Choices – use your postcode to search for local home care services. Each homecare service listing will provide contact details, whether the service is accepting new clients, ratings from people who've used the service and whether the service meets the Care Quality Commission national standards. <https://www.nhs.uk/conditions/social-care-and-support-guide/care-services-equipment-and-care-homes/national-homecare-providers/>

### **For care outside of the home, e.g. respite/short breaks and Residential care**

**Care choices** <https://www.carechoices.co.uk/>

For information and advice about arranging care and support services, this website can help you. Care Choices is a specialist information provider for care of the elderly and the specialist care of adults with additional needs (aged 18 – 64) in all types of care settings from care in your own home to care homes or independent living alternatives.

**Care Home** <https://www.carehome.co.uk/>

A searchable database of care homes throughout England and CQC reports, reviews and recommendations

**CQC** (Care Quality Commission)

<https://www.cqc.org.uk/what-we-do/services-we-regulate/find-care-home>  
03000 616161

email: [enquiries@cqc.org.uk](mailto:enquiries@cqc.org.uk)

The independent regulator of health and social care in England. They make sure health and social care services provide people with safe, effective, compassionate, high-quality care and encourage care services to improve. They monitor, inspect and regulate services to make sure they meet fundamental standards of quality and safety and publish what they find, including performance ratings to help people choose care.

**Person Shaped Support (PSS)** <https://psspeople.com/>

PSS have bases in England, Scotland and Wales. Helping to provide short breaks and shared living.

**Shared Lives plus** <https://sharedlivesplus.org.uk/>

General Enquiries Information Request 0151 227 3499

Email: [info@sharedlivesplus.org.uk](mailto:info@sharedlivesplus.org.uk)

Twitter: @sharedlivesplus

Shared Lives Plus runs a number of helplines. All of them are .....

### Office of the Public Guardian

0300 456 0300 Email: [customerservices@publicguardian.gov.uk](mailto:customerservices@publicguardian.gov.uk)  
Monday, Tuesday, Thursday, Friday, 9am to 5pm Wednesday, 10am to 5pm

### Guardianship (Scotland) <http://www.publicguardian-scotland.gov.uk/>

This website provides a single information point about financial provisions contained in the Adults with Incapacity (Scotland) Act 2000.

### Care and Health Law <https://www.schwehroncare.co.uk/>

Belinda Schwehr Email: [belinda@careandhealthlaw.com](mailto:belinda@careandhealthlaw.com)  
This website which provides up-to-date news and information on law, policy and practice developments relating to social and health care provision in the UK. Advice is a charged for service.

### Disability Law Service <https://dls.org.uk/>

Free Legal Advice 0207 791 9800 Email: [advice@dls.org.uk](mailto:advice@dls.org.uk)  
DLS runs a national advice line which is available from: Monday to Friday  
10.00am - 1pm and 2.00pm - 5pm.  
DLS provides free legal advice in the following areas of law:

- ♦ community care law (advice and representation)
- ♦ employment law (advice and representation)
- ♦ disability discrimination (advice and factsheets)
- ♦ welfare benefits (advice and factsheets)

### Disability Rights UK <https://www.disabilityrightsuk.org/>

**Office Number:** 020 7250 8181 (this line open Mon-Fri, between 10.00 and 12.30pm and 1.30 and 4.00pm). This line is not an advice line.

**Email:** [enquiries@disabilityrightsuk.org](mailto:enquiries@disabilityrightsuk.org)

DRUK is led by people with diverse experiences of disability and health conditions, from different communities.

### Luke Clements <http://www.lukeclements.co.uk/>

Luke Clements is the Cerebra Professor of Law at Leeds University where he has a Chair in Law and Social Justice. Luke is also a solicitor with Scott-Moncrieff & Associates Ltd.  
There are lots of very useful resources on his website.



- ♦ there are no objections to your appointment.

If you're appointed, the Office of the Public Guardian will help you carry out your responsibilities. You may have to complete an annual report. You'll continue to be a deputy until your court order is changed, cancelled or expires.

### Other ways to make decisions for someone

If you want to make a single important decision, you can apply to the Court of Protection for a one-off order.

### Who can apply to be a deputy?

You can apply to be a deputy if you're 18 or over. Deputies are usually close relatives or friends of the person who needs help making decisions. If you want to become a property and affairs deputy, you need to have the skills to make financial decisions for someone else. The court can appoint 2 or more deputies for the same person. The court will tell you how to make decisions if you're not the only deputy. It will be either:

- ♦ together (usually called 'jointly'), which means all the deputies have to agree on the decision
- ♦ separately or together, which means deputies can make decisions on their own, or with other deputies.

### Other types of deputy

Some people are paid to act as deputies, e.g. accountants, solicitors or representatives of the local authority.

The Court of Protection can appoint a specialist deputy (called a 'panel deputy') from a list of approved law firms and charities if no one else is available.

### Responsibilities

As a deputy, you're responsible for helping someone make decisions or, making decisions on their behalf.

You must consider someone's level of mental capacity every time you make a decision for them. You can't assume it's the same at all times and for all kinds of things. You'll get a court order from the Court of Protection which says what you can and can't do.

### When you're making a decision, you must:

- ♦ make sure it's in the other person's best interests
- ♦ consider what they've done in the past
- ♦ apply a high standard of care - this might mean involving other people, e.g. getting information from relatives and professionals e.g. doctors or therapists.
- ♦ do everything you can to help the other person understand the decision, e.g. explain what's going to happen with the help of pictures or sign language.

### You must not:

- ♦ restrain the person, unless it's to stop them from coming to harm
- ♦ stop life-sustaining medical treatment

- ◆ take advantage of the person's situation, e.g. abuse them or profit from a decision you've taken on their behalf
- ◆ make a will for the person, or change their existing will
- ◆ make gifts unless the court order says you can
- ◆ hold any money or property in your own name on the person's behalf (except if they live at home and you receive welfare benefits for them to pay for care, etc.).

### Property and affairs deputies

You must make sure:

- ◆ your own property and money is separate from the other person's
- ◆ you keep records of the finances you manage on their behalf

You may need to manage a Court Funds Office account on the other person's behalf.

### Apply to be a deputy

You can go to the government website

<https://www.gov.uk/become-deputy/apply-deputy>

to download and fill in:

- ◆ an application form (COP1)
- ◆ an assessment of capacity form (COP3)
- ◆ a deputy's declaration (COP4)
- ◆ an information form (COP1A) if you're applying to be a property and affairs deputy
- ◆ an information form (COP1B) if you're applying to be a personal welfare deputy

Send the originals to the Court of Protection with:

- ◆ 2 copies of your application form
- ◆ 1 copy of the other forms
- ◆ a cheque for the application fee

Court of Protection, PO Box 70185, First Avenue House, 42-49 High Holborn, London WC1A 9JA

The court will aim to send you a stamped copy of your application within a week of receiving it. This means your application is being considered (it has been 'issued'). You'll be sent a letter explaining what to do next. Within 14 days of the application being issued, you must tell (sometimes called 'serving') the following people :

- ◆ the person you're applying to be a deputy for
- ◆ anyone named in your application as having an interest, e.g. the person's close relatives

## Lasting power of attorney

This might not necessarily apply to most adults with a chromosome or gene disorder, but it might apply to some, hence why I have included this information in this guide.

A lasting power of attorney (LPA) is a legal document that lets your child (the 'donor') appoint one or more people (known as 'attorneys') to help

them make decisions or to make decisions on their behalf. This gives them more control over what happens to them if, for example, they have an accident or an illness and can't make decisions at the time they need to be made (they 'lack mental capacity').

**Your child must be 18 or over and have mental capacity (the ability to make their own decisions) when they make their LPA.**

There are 2 types of LPA:

- ◆ health and welfare
- ◆ property and financial affairs

They can choose to make one type or both.

There's a different process in Scotland:

<http://www.publicguardian-scotland.gov.uk/>

and Northern Ireland:

<https://www.nidirect.gov.uk/articles/managing-your-affairs-and-enduring-power-attorney>

### How to make a lasting power of attorney

Choose your attorney (you can have more than one). Fill in the forms to appoint them as an attorney. Register your LPA with the Office of the Public Guardian (this can take up to 12 weeks). It costs about £120 to register an LPA, unless you get a reduction or exemption.

#### 1. Health and welfare lasting power of attorney

Use this LPA to give an attorney the power to make decisions about things like:

- ◆ your child's daily routine, e.g. washing, dressing, eating
- ◆ medical care
- ◆ moving into a care home
- ◆ life-sustaining treatment

It can only be used when your child is unable to make their own decisions.

#### 2. Property and financial affairs lasting power of attorney

Use this LPA to give an attorney the power to make decisions about money and property for your child, for example:

- ◆ managing a bank or building society account
- ◆ paying bills
- ◆ collecting benefits or a pension
- ◆ selling the donor's (your child's) home

Both LPA's can only be used after they have been registered with OPG, then

- ◆ P&FA – can be used by an attorney even when the donor (your child) still has mental capacity, but
- ◆ H&W – cannot be used by an attorney whilst the donor still has mental capacity

Contact the Office of the Public Guardian if you need help and to find out more information on fees.