

So you can be
you



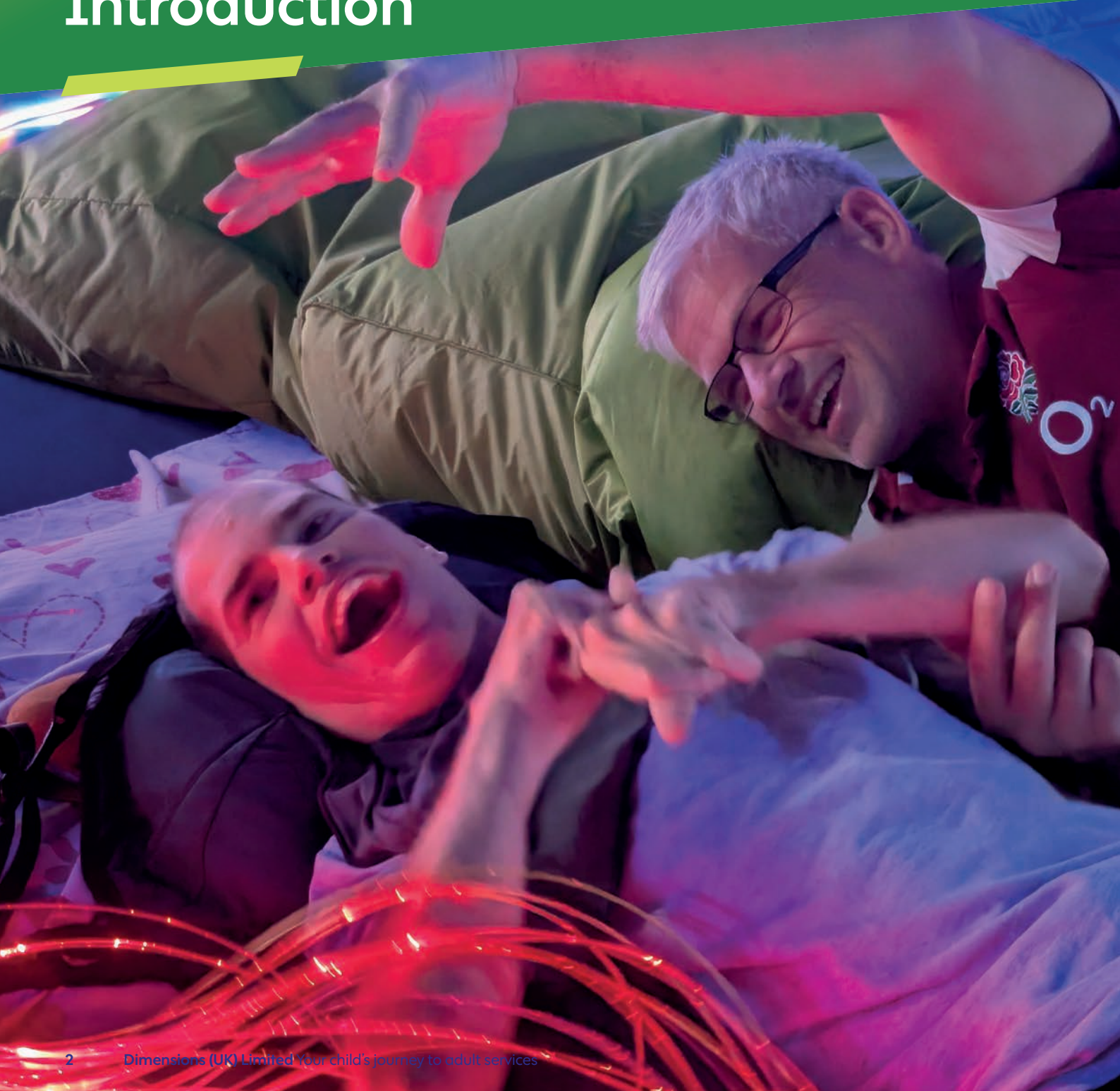
Transition

Your child's journey
to adult services



This guide aims to help you navigate the journey into adulthood and what choices are available. It has been written with the involvement of both families and a range of professionals, aiming to make a complex time as simple as possible.

Introduction





Please note: local arrangements can vary across the country so you should use this guide as the starting point for how you work with local services.

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Transitions

Getting started

If your child is likely to need support from adult social care services, your local authority should carry out an eligibility assessment before they reach the age of 18.

This also applies whether your child has an Education Health and Care Plan (EHCP).

So where do I start?

It helps if you start to think about your child's adult life around the age of 13 or 14 when they have their annual Education, Health and Care Plan (EHCP) assessment. You'll find that this may be the conversation to determine what options are best for them when it comes to planning ahead and preparing them for adulthood (19 – 25 years of age).

The special educational needs and disability (SEND) code of practice: 0 – 25 years (which supports the new law) says preparing for adulthood means:

- higher education and/or employment
- independent living (being as independent as possible with the right support)
- participating in society: friendships and contributing to the local community
- being as healthy as possible now and in the future.





How will my council help?

To get the support and care needs known and understood by the local authority in time to support them from age 18, you or your child can ask for a social care assessment from age 17 to determine what adult support could be provided; this is something the Care Act 2014 tells your local authority to carry out (but don't wait for them to contact you about it).

Someone in the adult social services department carries out the assessment; this will be an Adult Social Care Social Worker or it might be a dedicated transitions lead.

It is helpful to have read the eligibility criteria before the assessment.

The assessment will gather information on your child's needs and eligibility for care and support when he/she turns 18, as well as providing an indication of the different types of support available.

Local authorities have a duty, specified in the SEND Code of Practice, to:

- involve the person and family in the process
- provide impartial information
- work with health services to make joint commissioning arrangements around Education, Health and Care (EHC) for positive adult outcomes.

To help with achieving some of these duties they must publish a 'Local Offer'. This should provide up to date and comprehensive information on what support is available for children and adults up to the age of 25 as well as listing local arrangements and support providers.

Your child's social worker/care manager (if they have one) remain his or her allocated worker until they turn 18.

Some local authorities provide an allocated worker from 18 – 25. You may be allocated a social worker from the adult social care team if you haven't had a social worker before.



Each LA has a responsibility to manage transition out of school for pupils with an EHCP, although the provisions in place can vary.”



Understanding adult support

There are very many models of support. The list below covers the majority of support offered across the country but, depending on where you live, you may find your local authority has a slightly different approach.

24/7 support

may be provided with team members sleeping over at night.

Outreach

People who live independently in their own homes or with friends or family may need regular support with aspects of daily living such as personal finances, shopping or cooking. Sometimes known as domiciliary care, floating support or outreach and provides tailored support that meets an individual's identified needs.

Supported living/ Independent Living

Many people will continue to live in the family home, or live in their own home, that they rent or own.

The person should have a say in who they choose to live with if there is a spare room. Some people may have 24-hour support with team members sleeping in or being awake at night. Others may just have a few hours of support.

People who have behaviours of distress (sometimes referred to as challenging behaviour), or who have complex health needs, can often be supported in this way.



Resources

- Overview of support options: <https://www.dimensions-uk.org/who-we-support/>
- Choice forum: <https://www.choiceforum.org/>
- Parent Carer forum: <http://www.nnpcf.org.uk>
- Independent living: <https://www.ndti.org.uk/resources/preparing-for-adulthood-all-tools-resources/pfa-independent-living>
- Supported employment: <https://www.base-uk.org/about-supported-employment>
- Shared lives: <https://sharedlivesplus.org.uk/>



Short breaks are a great way to make new friends, try different things, and, in some circumstances, to prepare for living independently.”

Short breaks

Short breaks services (sometimes known as respite), are designed to give individuals and their families a break. A short breaks service offers a change from daily routines and many people are regular visitors. Short breaks are a great way to make new friends, try different things, and, in some circumstances, to prepare for living independently.

Residential care

Whilst supported living is generally the option that helps people to gain the greatest independence, residential care (in a small, permanently staffed home of generally two to six people) may sometimes be a preferred alternative based on an individual's needs.

Long stay hospitals and Assessment and Treatment Units (ATUs)

If a person experiences a crisis and poses a danger to themselves or others they may be sectioned under the Mental Health Act and detained in an Assessment and Treatment or secure unit. Although people can be detained over a long period, a hospital is not a home. People can and must be supported to move back into the community with the right support package as soon as possible.

If your loved one enters an ATU, you can use the mandatory Care and Treatment Review to develop a plan for discharge from the very start. Ideally before they go in.

<https://bringingustogether.org.uk/a-family-survival-guide-care-and-treatment-reviews-ctrs/>

Supported employment

This is a successful model for supporting people with significant disabilities to secure and retain real paid employment. There are eligibility criteria which, if met, mean the service is likely to be free. However, if this isn't granted, your personal budget or the Education, Health and Care Plan (EHCP) could be used to purchase this support, or you may be able to apply for an Access To Work grant.

<https://www.gov.uk/access-to-work/eligibility>

Support, care or service providers are terms used more or less interchangeably for organisations that provide support to people with additional needs such as people with physical and sensory impairments, people with learning disabilities and autistic people.



Support Provider or Personal Assistant?

Support providers may be profit-making companies, registered charities or have other not-for-profit arrangements. Some are very small and others support thousands of people across the country.

Many people choose not to use a support provider, preferring instead to employ a personal assistant to support their loved one directly, using the budget defined by the Local Authority as a Direct Payment.

What should I look for in a provider?

Of course you want a provider that will support your child to be happy, healthy, active and to achieve the outcomes in their Education, Health and Care (EHC) Plan and more, as they move through life. The big question is how can you tell which of the many available providers will give the best support?

You can have a look at the Care Quality Commission (CQC) website (CIW in Wales) to see what the most recent report says as a starting point. However, do your own research too. Speak to people in your area who receive support from different providers and hear what they have to say about the quality of support, but also about how well they work in partnership with families and how they respond when things go wrong.

Whether your child is going to be supported from the family home, live in a shared house or on their own, it is important that support is designed around their individual needs as well as their skills, interests and hopes for the future. This is called 'personalisation'. Particularly when someone has complex communication, good providers also work closely with family, friends and those who know them best.

How to engage with support providers

Most local authorities operate an Approved Provider List for providers of support and care to autistic people or people with learning disabilities. This is a list of organisations offering homes and services which have been assessed as meeting an acceptable standard of quality by the Council's Commissioning Team – a provider framework.



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“

These two options give you the greatest amount of control and responsibility.”

Sometimes it is possible to choose a provider that isn't on the list.

You can contact a support provider directly to start initial conversations to help confirm suitability and what funding options are available.

Personal assistants

A personal assistant is someone employed to help a person with support needs to live their daily lives. They might provide help with personal care, daily living, social and leisure activities and a host of other things as required. A personal assistant can be employed by a disabled person or their representative (e.g. parent). They are usually funded by a Direct Payment from social care but sometimes people fund them privately.

Your local authority should have a Direct Payments team who can offer some assistance with finding and managing staff. They will also clarify your legal responsibilities and offer a payroll service. Many areas have Independent Support Brokers who charge a small fee (usually taken from the Personal Budget) who can find and manage personal assistants or support workers' PAs for you.

These two options give you the greatest amount of control and responsibility.

Whether you decide to recruit and manage a support worker yourself, or go through a support provider or an agency, it is important to get the right person for the job. There are pros and cons to both options. A lot will depend on your circumstances, the kind and amount of support you need and the general availability of good people looking for this kind of employment.



Resources

- How to choose a support provider: <https://www.vodg.org.uk/resource/new-resource-top-ten-tips-when-choosing-a-support-provider.html>
- CQC: <https://www.cqc.org.uk/publications/themed-inspection/review-learning-disability-services>
- Employing a personal assistant: <https://www.equallives.org.uk/payroll-and-finance>

The story of how Dimensions is turning around the life of one young man, helping him achieve greater independence and living the life he chooses.



Believing in better?

Jason (not his real name) is an 18-year-old man whom we recently supported with his transition from education. Jason is autistic, has ADHD and pathological demand avoidance (a profile that describes those whose main characteristic is to avoid everyday demands and expectations to an extreme extent), which has led to behaviours of distress, including physical violence. Due to this, Jason spent a lot of time in hospitals when he was younger.

The local authority had been struggling to find the appropriate support for Jason and that is where we stepped in. After meeting with the multi-disciplinary team and key professionals we planned for Jason's transition from school.

While lots of 'what ifs' were discussed in the meeting, so were the possibilities.

One support worker, Emma saw many opportunities for Jason; to build on his skills, offer him more choices and support him in doing more of what he enjoys.

She was determined that he should lead a more independent life and was confident that with the right support, he would be able to achieve this.



Emma says:

Working together has been a learning curve for both Jason and I. It has been great understanding his specific needs and how he comprehends the world. Jason has learned to socialise and how to interact with others. In doing so he is enjoying a variety of new activities he would never have thought of doing. Jason now looks forward to his day and is excited to get up in the morning because he knows he will have a fun filled day with someone who understands him."

Opportunity

We spotted opportunities for Jason to build on his skills and offer him more choice in doing what he loves.

Since his transition to Dimensions six months ago it is clear that Emma and Jason have developed a great rapport. Jason has not displayed any behaviours of distress and is accomplishing many new things. Jason has really enjoyed learning to cook with Emma, mac and cheese being his ultimate favourite and he has also enjoyed baking cakes for his family.

Jason has been getting involved with many more activities and loves bowling and hiking. He even managed to hike Roseberry Topping, a local beauty spot with Emma.

Jason's family are really pleased with how smoothly the transition has gone and have seen a noticeable difference in Jason. The positive behaviour support he has received and the implementation of Activate – Dimensions outcome-focused model of support has meant he has not experienced any previous behaviours of distress. When Jason was at school he didn't want to get out of bed in the morning, but now he jumps out of bed raring to go.



Jason's mother said:

Jason had been at the same school since he was four, everyone knew him and understood his needs, so I was extremely anxious about him leaving. I worried that accessing adult services would be difficult for him and cause him anxiety, which could lead to him becoming aggressive. However he's doing great! His support worker Emma is the best he's had. She has quickly bonded with him and learned how to communicate with him. She picks up when he's anxious and spots things that will trigger him. This helps because it is better to prevent Jason getting stressed than to have to calm him. She regularly communicates with me about how best to support him. They have a great bond and Jason says, "Emma's my bestie." Emma is amazing, a genuine carer, this seems to be much more than just a job to her and I can't thank her enough."



**Emma's my bestie.
Emma is amazing,
a genuine carer**

Jason



In the past, when most people with learning disabilities and autism lived in residential care and had a small weekly personal allowance, there was simplicity of sorts. But, there was also very little choice about how people could spend their lives, let alone their money.



Money matters

Over the years there have been a lot of changes to how support is provided and things that used to be free, like day services and transport, now usually have a cost attached. People use a combination of their benefits and personal budget to pay for activities like day services and classes, as well as ordinary activities like going to the cinema, bowling or having a night out. This generally gives a better standard of living, as well as more choice and control, than in residential care.

But managing your child's money can be one of the most complicated roles for a parent.

This section provides a short introduction to some of the things you will need to think about, and we hope the additional resources we've suggested will help further.



Managing your child's money can be one of the most complicated roles for a parent."

Benefits

Upon turning 16 your child has the same right to claim benefits or to stay in full time education as anyone else. Benefit entitlements (and names) are continuously changing – **see resources** for the most up to date links.

At the time of writing some of the main benefits to be aware of are:

- Disability Living Allowance (DLA) or Personal Independence Payments (PIP)
- Attendance Allowance
- Employment and Support Allowance
- Housing benefit
- Universal Credit

NB: An award of ESA to the child means that any benefits parents get for their child (e.g. child benefit, tax credits) will stop. Take care to make sure your family won't be worse off!

An organisation called Contact has a great benefits helpline to check:

Tel: 0808 808 3555 or

Visit: <https://contact.org.uk/help-for-families/information-advice-services/benefits-financial-help/>

Paying for support

Having assessed your child's needs, your local authority will then allocate a Personal Budget designed to meet those needs. This money comes from either Social Services or Health – or a mixture of both. A health budget is called Continuing Health Care (CHC).

Your child can then spend their Personal Budget on services that meet their needs. This may include employing someone to support them such as a personal assistant, in addition to equipment, adaptations, transport, training, accommodation, activities



Resources

- Dimensions' Money Matters factsheet: <https://www.dimensions-uk.org/resource/facts-for-families-money-matters/>
Personal Budgets: <https://www.disabilityrightsuk.org/resources/personal-budgets-right-social-care-support>
- Benefits: <https://www.gov.uk/browse/benefits/disability>
- Direct Payments: <https://www.carersuk.org/help-and-advice/practical-support/arranging-care-and-support-for-someone/direct-payments/>

and so on. Detailed decisions about how the money is spent are usually taken as a group that includes the funder together with your child, and you.

The Personal Budget may be made as a Direct Payment, or may be spent by the local authority on your child's behalf. Direct Payments put you in control but you may prefer others to manage this. In particular, not everyone wants to take responsibility for recruiting and employing support workers for their child.

Personal Budgets are reviewed every year. Additional reviews can take place if your child's needs change; talk to your social worker /transitions worker to plan the meeting.

Direct Payments

A Direct Payment is a cash payment from a local authority to enable people to purchase their own services. A Direct Payment is available to anybody aged 18 – 64 who, following a support and needs and eligibility assessment, needs community care support services. A Direct Payment is not a social security benefit, and receiving one will not affect your child's benefits entitlement.

Direct Payments must be used to purchase support to meet the person's assessed needs. Some providers, including Dimensions, can manage direct payments on behalf of the individual.

Managing money

It can feel like an arduous process to establish arrangements with banks and others for managing money on behalf of your child. Good support providers will welcome your involvement in managing your child's money and will be able to guide you over the various hurdles.

You can play a number of different roles to support your child with their finances:

- Be a court appointed deputy (to manage all financial affairs, including a Personal Budget) <https://www.gov.uk/become-deputy>
- Be an appointee (to manage benefits) <https://www.gov.uk/become-appointee-for-someone-claiming-benefits>
- Being granted Power of Attorney <https://www.gov.uk/power-of-attorney>
- Keep an informal 'watchful eye' (with your relative's permission)
- Attend planning and review meetings and participate in decision making.



Help with housing

Most adults with learning disabilities or autism want to live in an ordinary house or flat (with as much or as little support as they need) fairly close to where they grew up, near to family and friends.

Like any other child becoming an adult, the timing of when they leave home is a mixture of personal choice, family circumstance and the availability of housing, support and the money to make it happen.

Cost is only one factor in decisions about living arrangements; individual needs and wellbeing must be taken into consideration, as well as local availability. In most situations the cost is met by health or social services.

Your child's support needs assessment (which you can challenge if you think it is wrong) will act as a guide to the various housing options that are open to you. This, or the annual review of your child's Education Health and Care Plan, is a good starting point for a conversation about future living and housing options.

There are some key things to think about to make sure you make the best decisions:



Live alone or share?

When people want to live with others, choosing the right house-mates is just as important as the right building. Compatibility, shared interests and lifestyles all help to make a shared house a happy place. Like anyone else, people with learning disabilities and autism can choose to live with friends when they first leave home and move on to live with a partner or alone as they grow and change.

Often people share a house, typically with two to five people each having their own bedroom, in a supported living set up. The rest of the property is communal space used by tenants collectively and normally this will include at least a lounge, kitchen and dining area. Each person will have an established and funded level of staff support from visiting (one to two hours) to 24 hour presence.

Timescales

It's unlikely that you will be able to plan to a precise date, but having a broad idea will help you get everything in place. It's not just about housing and support; everyone will probably have some emotional preparations to do and some people will really enjoy gathering household items for their new home in the months before the big move.

Do your research

Other families are a great source of information. Talk to people whose children have moved away from the family home both in your area and further afield. If you find out about options that aren't available locally to you then ask if it's possible. You will probably hear about some situations where things haven't worked out so well. Use those stories to help you put a good list of questions together. Knowing what you want to avoid is as important as knowing what you want.



Each person will have an established and funded level of team support.”

Paying for housing

People in supported living are usually eligible for housing benefit to cover rent costs.

It is possible for people with learning disabilities and autism to get a mortgage through My Safe Home <https://mysafehome.info/> proving a variety of schemes such as shared ownership, which may also be covered by housing benefits.

Your son or daughter might be offered a place in an existing supported living scheme or residential care home. If you are all happy with the place being offered then this is a simple option.

If not, there are a number of ways to get a house for one or a small group of people:

- For living alone, you could put your name down and bid for Social Housing (**Housing Association or Council properties**) through your **local key choice scheme** or rent through the **private market**
- Use an organisation like **Lets for Life** to find and manage a property for you
- Work with your chosen support provider to find a house via your **local authority specialist housing team**.



Resources

Learning Disability England: <https://www.learningdisabilityengland.org.uk/welcome/policy-and-taking-action/campaigning/housing-choices/>

Mencap: <https://www.mencap.org.uk/advice-and-support/housing/housing-faqs>

This section aims to give a very brief introduction to some relevant pieces of legislation with links to helpful resources we've found:



Make the most of the law

The Children and Families Act

The Children and Families Act (2014) says that all young people and their parents have the right to have high expectations for their future. Young people with special educational needs and disabilities (SEND) may face additional barriers and challenges to achieving their goals. Preparing for adulthood means identifying the support a young person will need to live as full and active an adult life as possible.

Young people should be at the centre of planning for and making decisions about their future. Discussions should focus on what they want to achieve, and the support they will need to get there.



Preparing for adulthood means identifying the support a young person will need to live as full and active an adult life as possible.”

There is now a single system of support for children and young people with SEND between the ages of 0 and 25. This means that no one should lose the right to extra support for their educational needs simply because they have reached 16 or left school. Further education colleges and settings now have similar duties to schools to support students with SEND.

The special educational needs and disability code of practice: 0 – 25 years (which supports the new law) says preparing for adulthood means preparing for:

- higher education and/or employment
- independent living
- participating in society: friendships and contributing to the local community
- being as healthy as possible in later life.

The Mental Capacity Act

The Mental Capacity Act (MCA) 2005 applies to everyone involved in the care, treatment and support of people aged 16 and over living in England and Wales who are unable to make all or some decisions for themselves. The MCA is designed to protect and restore power to those vulnerable people who lack capacity.

This Act affects decision-making for all people aged 16 and over who are unable to make some or all decisions by themselves. The issue of capacity is decision-specific; this means that capacity can only be assessed in relation to a particular decision that needs to be made at a particular time. This is an important safeguard against blanket assessments of someone's ability to make decisions based on their disability. It also recognises the fact that someone may be able to make some decisions but not others.



Resources

- SEND Code of Practice: <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>
- Mental Capacity Act: <https://www.scie.org.uk/mca/introduction/mental-%20capacity-act-2005-at-a-glance/>
- Care Act: <https://councilfordisabledchildren.org.uk/resources/all-resources/filter/statutory-guidance/2014-care-act-easy-read>

For example; someone can lack capacity to make complex financial decisions or consent to medical treatment, but have the capacity to decide what they would like to eat.

When assessing capacity to make a decision, it is important to consider whether your child is able to:

- understand the information relevant to the decision
- retain that information
- use that information to make a decision
- communicate their decision, whether by talking, using sign language or any other means.

When someone is judged not to have the capacity to make a specific decision (following a capacity assessment), that decision can be taken for them, but it must be in their best interests. The process of making a best interest decision should be led by the person who requires the decision to be made; e.g. a doctor who requires consent before carrying out treatment. There must be a record of how the decision came to be made.

Consulting with others is a vital part of best interest decision-making, and the Mental Capacity Act requires the involvement of people that know the person best, such as carers and family members. Parents and professionals must always support a young person to be involved as much as possible in a decision made on their behalf, even if they do not have the capacity to make it themselves.

The Care Act

The Care Act 2014 sets out in one place local authorities' duties in relation to assessing people's needs and their eligibility for publicly funded care and support.

Under the Care Act 2014, local authorities must:

- carry out an assessment of anyone who appears to require care and support, regardless of their likely eligibility for state-funded care – including unpaid carers.
- focus the assessment on the person's needs and how they impact on their wellbeing, and the outcomes they want to achieve
- involve the person in the assessment and, where appropriate, their carer or someone else they nominate
- provide access to an independent advocate to support the person's involvement in the assessment if required
- consider other things besides care services that can contribute to the desired outcomes (e.g. preventive services, community support)
- use the new national minimum threshold to judge eligibility for publicly funded care and support
- continue providing support through the assessment process until adult services are in place to take over – or until it is clear after the assessment that adult care and support will not be provided, there should be no gap in services.



Reducing behaviours of distress through Positive Behaviour Support

Paul would violently self-harm when we first started supporting him. Through Positive Behaviour Support, he's much happier.

Paul is a young man who came to Dimensions straight from school. With a complex mix of behaviours of distress, we saw opportunities to use Positive Behaviour Support techniques that have vastly improved his wellbeing, life and relationships.

Paul could only deal with a very limited amount of stimulation and would become very agitated if any of his belongings were moved.

Sadly, he also became agitated by his parents. This meant he could only visit them for a few minutes before getting upset and having to leave.

These triggers caused not only his distress but also his self-harm. When he was unhappy, he'd often hit his head against hard walls, damaging property as well as his own wellbeing.

Our specialist team of behaviour analysts worked with him, his family and his support team on a number of approaches to reduce his self-harm, aggression and triggers. These included being matched to a calm and observant support worker, achieving personalised approaches of communication, and taking change at a pace comfortable to Paul.

He is now much happier, gets on well with his parents and his self-harm has reduced significantly.

Paul's progress

He now trusts those around him and understands his own triggers. He has rebuilt his relationship with his family and much less self harming





Family checklist

from Child to Adult Services

	Things to do	Done
13 – 14 years	Check out my council’s “Local Offer” on their website (see what’s on offer for 16+ years)	
	Know the main provisions of the Children’s & Families Act 2014	
	Support my child to open a bank account before they turn 16	
	Begin thinking about what support my child will need when they’re an adult at the year 9 Education, Health and Care Plan (EHCP) annual review	
	Meet Transition social worker (if they have them in my area)	
	Find out my, and my child’s, rights – The Care Act 2014	
	Consider getting a carers assessments (especially if my child doesn’t have a social worker)	
14 – 16 years	Learn about the different models of support – care homes, supported living, outreach, personal assistants – and begin to think about what might be best for my child	
	Learn about different housing arrangements, and begin to think about what might work best for my child	
	Ask for my local authority’s Approved Provider List and take a look at the Care Quality Commission website to find out how some of these are currently rated	
	Check out benefits. Learn what these are, and how entitlements differ depending on what model of support my child might receive	
	Learn about the difference between Direct Payments and a Personal Budget, and think about what is going to work best for me and my child.	
	Know the difference between being a Court-Appointed Deputy, Power of Attorney for Health and/or Finance and an Appointee; think about what is might work best for me and my child	
	Learn about my, and my child’s, rights and responsibilities under the Care Act	
	Understand how the Mental Capacity Act applies to me and my young person	



Family checklist

from Child to Adult Services

16 – 18 years	Things to do	Done
	Add my child's name to the local council's housing list (this is done in the same way for everyone)	
	Check the local eligibility criteria for adult support, then arrange for a social care assessment from local authority for my child (around their 17th birthday) with my council.	
	Research adult short breaks (Children's short breaks aren't always available to over 18s)	
	During the last two years of education: ensure that a social worker is working with us to lever the right support (Ideally this would be a Transition social worker)	
	Schedule the final Education Health and Care Plan review for first term of my child's last year of education.	
	Find out what adult services are available in my area: <ul style="list-style-type: none"> • Meet care and support providers • Outreach (regular day support) starts at 18yrs to ensure a consistent approach • Employment/Supported employment • Supported Living • Further educational options and opportunities 	
	Learn about the appeals process in case we don't agree with the funding allocated	
	Maintain contact with my social worker. Make sure that all the right people are at any transition/school meeting	
	Consider transport costs and arrangements in all plans	



Resources

Throughout this document we've tried to direct you to the best resources on each topic.

In this section we provide summary details of particularly helpful organisations.

- The Dimensions website has extensive resources designed for the families of people we support and others, covering a very wide range of important topics and including a jargon buster: www.dimensions-uk.org and [click on Good to know/ Family partnerships](#).
- Preparing for Adulthood is an organisation funded by the Department of Education (DfE) delivered by the National Development Team for inclusion: <https://www.ndti.org.uk/resources/preparing-for-adulthood-all-tools-resources>
- The Council for Disabled Children is part of the National Children's Bureau and have useful information on preparing for adulthood: <https://councilfordisabledchildren.org.uk/adulthood>
- Learning Disability England is a user-led membership organisation which does excellent campaigning work and is particularly strong on housing: <https://www.learningdisabilityengland.org.uk/campaigning-and-influencing/housing-choices/>
- The National Network of Parent Carer Forums can help you get in touch with other parents in your area who may be in a similar position to you: <http://www.nnpcf.org.uk>
- Healthwatch England is a national independent champion for people who use health and social care services: <http://www.healthwatch.co.uk>
- The National Institute for Health and Care Excellence publish guidelines which offer evidence based recommendations on various topics. <https://www.nice.org.uk>
- Specialist financial advocacy from Dosh: <http://www.dosh.org/>
- Family Carers advice and support at <https://www.hft.org.uk/>
- Skills for Care provide practical tools and support for organisations and individuals who employ staff: <http://www.skillsforcare.org.uk>
- Dimensions transitions guide (downloadable version of this document): <https://www.dimensions-uk.org/wp-content/uploads/Transition-your-childs-journey-into-adult-services.pdf>

Blog article by Liz Wilson,
adult family member



Steering through the acts and policies out there

I found out about the Mental Capacity Act just as my daughter started secondary school and I have used the principles to guide my parenting through her teens to life now as a young adult.

It took a while to work out how to build it into our lives, but here's how it worked for us.

Assume she has the capacity to make decisions unless it is proved otherwise

Time and time again, my daughter had proven that she understood far more than she was able to express. I regularly got annoyed by others underestimating her so decided I needed to challenge my own thinking.

I got thinking about her safety and realised that being able to make choices and decisions, and to have them respected by everyone is a necessity.

We started off with small, safe choices:

- Carrots or sweetcorn?
- Red socks or blue socks?
- Park or swimming pool?

Everyday choices became routine and I learned to change my language to make sure I wasn't accidentally offering a choice when there was none, so 'shall we go to the supermarket' became 'we need to go to the supermarket.'

Now she is 21 and making much bigger decisions on a regular basis. Sometimes the decisions take ages to make and that can be frustrating for me (and others) but a slow decision is better than no decision. I don't always agree with my daughter's choices but we've got a process in place that we can share with others. Give all possible practical help to support decision making

My daughter's learning disability means she doesn't pick up information the way typical young people do. Everything has to be made explicit, and presented in different formats. Trial sessions at new activities can be more effective than talking about it. If it takes six months and the input of family and friends as well as practitioners to give her the chance to make a decision, then that's ok.

“

I don't always agree with my daughter's choices but we've got a process in place that we can share with others.”



“

The ‘unsuitable’ boyfriend was a hard one for me, but those lessons about having your choices listened to and respected, they paid off.”

Learning about healthy eating was particularly difficult as the main lesson that stuck was ‘a little bit of cake or chocolate every now and again is ok.’ ‘Little’ and ‘now and again’ are tricky concepts to understand so we put some ground rules in place for school lunches and have mainly healthy foods at home. Some health conditions mean weight gain could be particularly dangerous. It took seven years to get an understanding of ‘little’ and ‘now and again’ but what a fantastic life lesson that is!

I have adapted life to include a long run-up to big decisions. She doesn’t always make the decisions I would expect or choose but so far she’s got it right for herself. She’s really happy with her choice of college.

Don’t treat her as lacking capacity just because she makes an unwise decision

Who doesn’t hate their children – adult or little – making unwise decisions? I started small and winced at the clothes she bought when out with her cousin. I felt awful about

the shoes that made her feet bleed – but it was only once and now she’s happy to go to the shop that has wide fittings (it took me much longer to give up being a fashion victim to shoes!).

The ‘unsuitable’ boyfriend was a hard one for me, but those lessons about having your choices listened to and respected – they paid off! A bit of heartache is all part of the growing up process and much though I would like to protect her it’s not the right way to go.

I’m expecting to be challenged by unwise decisions many times as she moves away from home into supported living, but I know the processes we have for checking understanding and giving information will help to minimise the risks.

Anything I do on her behalf must be in her best interests

I used to think a person either had capacity or didn’t have capacity. One of the things I like about the MCA is that it looks at capacity on a decision by decision basis.

My daughter knows that money buys the things she likes but doesn’t understand budgeting or ‘value for money’. She knows what the separate coins and notes are but can’t hand over the right amount or work out and check her change. This makes her vulnerable to financial abuse – or being ripped off.

Since the age of 12 she’s had a cash-card account for her spending money.



By experiencing the ‘machine says no’ she has learned to look at her balance and ask ‘can I afford it?’”

There’s no overdraft facility so when it’s gone, it’s gone. By experiencing the ‘machine says no’ she has learned to look at her balance and ask ‘can I afford it?’ We talk together about what holidays and theatre shows she can afford to go to with her personal assistants.

I manage the serious end of the money, dealing with benefits, paying the phone contract and making any necessary larger purchases, in discussion with her whenever possible. All of her money is in a separate account to mine so I can clearly use it for her best interests. I’m hopeful that she will gain a bit more understanding of budgeting but expect her to need someone to take responsibility for overall management and safety of her money for the rest of her life.

General good health means I haven’t had to explore best interests decisions on that subject but it may be necessary in the future.

Sex and relationships

Recently I’ve had to think about the whole sex and relationships issue. It’s complicated!

Of course I want her to find love and happiness but she has a romantic and simplistic notion of what having a baby and being a parent mean. When the time comes there may be a need for some long term contraception while she learns more about the consequences of unprotected sex and/or develops the skills and understanding needed to raise a child with the limited amount of support that could be available (I’m not going to live forever...) I really hope that she will be able to come to her own decision that supports her best interests, but if not, then long term contraception will give her the freedom to enjoy a relationship without the indignity, pain and loss of having a child taken away because she can’t manage the complexities of parenting.



Budgeting

I’m hopeful that she will gain a bit more understanding of budgeting but expect her to need someone to take responsibility for overall management and safety.



Moving from school or college to a new home



Transition timeline

Stage	What happens	Time slippage	Red flag*
Assessment	<ul style="list-style-type: none"> • Assessment carried out • Environmental needs assessments • Collating all social/health care assessment e.g. SALT 		<ul style="list-style-type: none"> • Over stretched social worker unable to provide paperwork • Absence of behaviour data for analysis • Unable to spend time with the individual
Support design	<ul style="list-style-type: none"> • Develop support design with family/all stakeholders • Present proposal including time scales & costs to funders 		<ul style="list-style-type: none"> • Costs or timescales not agreed by funder
Property	<ul style="list-style-type: none"> • Housing specification agreed with all stakeholders • Search for property 	<ul style="list-style-type: none"> • Delay with funding for property • Unable to find suitable property • Property found but in large chain 	<ul style="list-style-type: none"> • Adaptations not agreed • Unable to secure funding
Getting to know 'you'	<ul style="list-style-type: none"> • Regular meetings between the family and manager • "Getting to know you" begins as time is spent with the individual 	<ul style="list-style-type: none"> • Appointment of experienced manager 	<ul style="list-style-type: none"> • Unable to appoint manager
Getting to know 'you'	<ul style="list-style-type: none"> • Property purchased • Builder sourced • House adaptations take place • Getting to know individual continues with regular visits • Regular transition meetings with Local Authority and CCG • Begin development of the individuals support plans and risk assessments 	<ul style="list-style-type: none"> • The property purchase is delayed • Tendering of building works is delayed • Building work is slowed e.g. bad weather 	

Stage	What happens	Time slippage	Red flag*
Support team	<ul style="list-style-type: none"> Recruitment begins: Must have 125% of permanent team in place before person moves in 	<ul style="list-style-type: none"> Lack of response to advert Lack of quality candidates 	
Property handover		<ul style="list-style-type: none"> Internal furnishings delayed e.g. Toughened furnishing is bespoke and takes eight weeks to order 	<ul style="list-style-type: none"> Exempt housing benefit not guaranteed
Induction	<ul style="list-style-type: none"> All team members start Attend bespoke specialist training Role play proactive / reactive strategies in situ Prepare property to be a 'home' Complete transition activities Develop pictorial aids and weekly activity plan 	<ul style="list-style-type: none"> DBS holds process up 	<ul style="list-style-type: none"> Adaptations not agreed Unable to secure funding
Move in date		<ul style="list-style-type: none"> Motability vehicle cannot be ordered until after move in day. 12 week order time Legal requirements not in place For example: Deprivation of Liberty Safeguards or Court of Protection application 	<ul style="list-style-type: none"> Full team must be in place Ordering an interim vehicle

Better Lives for More People

We're here, so that you can be you:

- You'll make more choices and so gain more control over your life.
- You'll have the support and the housing you need to lead a fun, safe, ordinary life.
- Your loved ones will be as much a part of your life as you both want.
- You'll take steps towards more independence, with the right sized support for you to really shine.
- You'll be at the centre of your own support plan. Everything about you, will involve you.

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