



## Transition

Your child's journey to adult services

# Introduction

We know how hard it can be to plan your child's transition from children's to adult services. This guide aims to help you understand the journey and what choices are available to you. 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.

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 must carry out an eligibility assessment before they reach the age of 18. This also applies if your child is not currently receiving children's social services or if they have an Education Health and Care Plan (EHCP).

### So where do I start?

You should start to think about your child's adult life ahead of their year 9 annual EHCP review (they will be 13-14 years of age.) This is the first 'official' 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).

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

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 now and in the future

## How will my Council help?

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.

Someone in the adult social services department will carry out the assessment; in some local authorities this person will be a dedicated transitions lead.

The assessment will provide information on your child's needs and eligibility for care 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, including 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 provides 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 will remain his or her allocated worker until they turn 18. Some local authorities provide an allocated worker from age 18 to 25, but many will not.

Your rights as a carer change when your child is an adult so seek help from a Carers service to understand these rights, especially the Wellbeing Principle.





# Understanding adult support

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

## Independent Living

Many people will be able to live at home or essentially independently, often benefiting from a personal budget based on their assessed need, for them to purchase the support they need directly, such as a place at a day centre. (see page 11 for info on personal budgets.)

## 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 or floating support, outreach provides tailored support that meets an individual's identified needs.

## Supported living

Supported living is where someone is provided with support in their own home, which they may own or rent. The person has a say in who they choose to live with should there be a spare room. Some people may have 24-hour support with staff sleeping in or being awake at night. Others may just have a few hours of support. People whose behaviour may challenge, or who have complex health needs, can often be supported in this way.

## Residential care

Whilst supported living is general the option that helps people to gain the greatest independence, residential care (in a small, permanently staffed home of generally 2-6 people) may sometimes be a preferred alternative based on an individual's needs.

## Short Breaks

Short breaks services, also known as respite care, are designed to give individuals and their families a break. A short breaks service offers a change from daily routines and many guests 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.

## 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.

## 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.

## Resources:

- Overview of support options: <https://www.dimensions-uk.org/what-we-do>
- Choice forum: <https://www.choiceforum.org/>
- Parent Carer forum: <http://www.nnpcf.org.uk>
- Independent living: <https://www.preparingforadulthood.org.uk/downloads/independent-living>
- Supported employment: <https://www.base-uk.org/about-supported-employment>
- Shared lives: <https://sharedlivesplus.org.uk/>



## Support Provider or Personal Assistant?

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 people with autism.

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 directly employ a personal assistant to support their loved one.

### 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 (CSSIW 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. Ask your local authority for the dates of their next parent carer forum.

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 is unable to communicate in any way, good providers also work closely with family, friends and those who know them best.

**“Personalisation is about putting individuals firmly in the driving seat of their own support.”**

## How to engage with support providers

Most local authorities operate an Approved Provider List for Learning Disabilities providers. This is a list of organisations offering services which have been assessed as meeting an acceptable standard of quality by the Council's Commissioning Team. 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 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 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 pro's and con's 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/wp-content/uploads/2017-VODG-Top-10-tips-when-choosing-a-support-provider.pdf>
- **CQC -** <http://www.cqc.org.uk/publications/themed-inspection/review-learning-disability-services>
- **BILD factsheets:** [www.bild.org.uk/information/factsheets/](http://www.bild.org.uk/information/factsheets/)
- **Employing a personal assistant:** <https://equallives.org.uk/info-and-advice/care-and-support/recruitment-and-employment/>



# Believing in Barbara: the story of how one woman has finally started living her life

This is the story of how Dimensions is turning around the life of one young lady who has autism and a learning disability.

After a string of failed placements, Dimensions has halved Barbara's staffing needs and costs – from 2:1 to 1:1 . She is now out, about and meeting all sorts of characters in her community.

Barbara, now in her mid-20s, has not had an easy life. Difficulties in school meant that she did not learn the relationship skills that most of us take for granted. Barbara's first supported living placement broke down when she was physically abusive towards others and age 21 she ended up being sectioned into an ATU where she lived for two years.

Dimensions met her at a residential home in Gateshead. The thing that struck us most about Barbara, was that no-one had anything nice to say about her at all. No-one around her seemed willing to build Barbara up, to find her strengths, to engage with her in the way she needs.

Due to her verbal and occasionally physical aggression, no-one even seemed prepared to encourage her to go outdoors; she may have been living in the community but she was most definitely not part of it. Often, Barbara lay in bed all day – she got up after 11am on three out of four days. Her staff seemed to have given up.

Given the right environment Barbara can be full of life, full of energy. When her support changed to Dimensions, and following our Functional Behaviour Assessment, our two top priorities were to get the right living environment, and the right staff around her.



Welbeck Road is a core-and-cluster house (five independent flats in the same complex). This gives it a nice community atmosphere, whilst also providing the independent living that is so important to Barbara.

She can spend time at home, and go round to any of the other four tenants to build friendships. As a group, they go to the dogs, have film nights and get together for all sorts of things. Barbara is even planning to go to a Little Mix gig this year.

Overall, 56 % of her waking time is now spent doing activities, compared to 14 % before Dimensions. And most days, she chooses to get up before 11am.

Getting the right staff for Barbara meant recruiting energetic, positive people. Staff who would make the effort. Who would not let setbacks get them down. Who could create the vibe that Barbara would respond to. Who are as full of beans as she can be. Who can help Barbara discover her own potential, and never, ever make her feel she's let them down.

One of the first things we did was to get a high-energy playlist together, which now gets Barbara out of bed and going in the mornings.

We have also devised an activity planner so that regardless of what time Barbara gets out of bed, there is a plan for something to do.

It was important for Barbara to take control of her life. She's very target driven. She monitors her own sleep, has decorated her own home, chooses and buys her own shopping and has recently joined Slimming World, while challenging herself with a new Fitbit. Indeed, since beginning her fitness programme, Barbara has reached her target each week.

She's going out every day and enjoys visiting her mum. And, she has already completed one college course with skills for people and is looking into enrolling onto another in the near future.

There's a long way to go. But Barbara's story shows just how important it is, for all of us, to be surrounded by people who believe in us.

**“Overall, 56 % of her waking time is now spent doing activities, compared to 14 % before Dimensions. And most days, she chooses to get up before 11am.”**



## Money matters

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.

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.

### 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 up to date links - but at 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

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!

### 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. Your child can then spend their Personal Budget on services that meets their needs. This may include employing someone to support them such as a personal assistant, in addition to equipment, adaptations, transport, training, accommodation, activities and so on. Detailed decisions about how the money is spent are usually taken as a group that includes the funder together with you and your child.

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 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 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)
- Be an appointee (to manage benefits)
- Keep an informal 'watchful eye' with your relative's permission
- Attend planning and review meetings and participate in decision making

## Resources:

- Dimensions' money matters factsheet: <https://www.dimensions-uk.org/families/plain-english-factsheets/>
- Personal budgets: [www.disabilityrightsuk.org/personal-budgetsthe-right-social-care-support](http://www.disabilityrightsuk.org/personal-budgetsthe-right-social-care-support)
- Benefits: [www.gov.uk/financial-help-disabled/disability-and-sickness-benefits](http://www.gov.uk/financial-help-disabled/disability-and-sickness-benefits)
- Direct payments: [www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/direct-payments](http://www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/direct-payments)



## 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. 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 well-being must be taken into consideration. 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 2 to 5 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 (1 to 2 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.

## 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 proving a variety of schemes such as shared ownership, which may also be covered by Housing Benefits.

The cost of Residential care is usually met by Health or Social Services. However, if you have been assessed as needing a care home place and your capital is below £23,250 (at time of writing), you should be entitled to financial support from your local authority.

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



## Make the most of the law

Our family consultant has written an interesting blog about how she has made the most of the law to support her daughter through transition. We have included it at the end of this guide.

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

### The Children and Families Act

The Children's 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 (SEN) 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.

There is now a single system of support for children and young people with SEN 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 SEN.

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. 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.

Consulting with others is a vital part of best interest decision-making, and the Mental Capacity Act requires the involvement of 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
- 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.



## Resources:

- SEN Code of Practice: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/398815/SEND\\_Code\\_of\\_Practice\\_January\\_2015.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf)
- Mental Capacity Act: <http://www.preparingforadulthood.org.uk/resources/all-resources/pfa-factsheet-the-mental-capacity-act-2005-and-supported-decision-making>
- Care Act: <http://www.preparingforadulthood.org.uk/resources/all-resources/the-care-act-2014-easy-read-guide>

# Reducing self-harm 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 challenging behaviours, we saw opportunities to use Positive Behaviour Support techniques that have vastly improved his well-being, 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 challenging behaviour 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 well-being.

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.

What has Paul achieved?

- Paul now trusts those around him and understands his own triggers
- He has rebuilt his relationship with his family
- There is significantly less self-harming behaviour and property damage, and very little risk of harm to others





## 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](http://www.dimensions-uk.org) and click on Families.
- Preparing for Adulthood is an organisation funded by the Department of Education (DfE) delivered by the National Development Team for inclusion: <http://www.preparingforadulthood.org.uk/>
- 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/our-work/adulthood>
- Learning Disability England is a user-led membership organisation which does excellent campaigning work and is particularly strong on housing: <http://www.housingandsupport.org.uk>
- 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.nnpf.org.uk>
- Healthwatch England is a national independent champion for people who use health and social care services: <http://www.healthwatch.co.uk>
- 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/>
- The Voluntary Organisations Disability Group (VODG) represent not for profit providers: <https://www.vodg.org.uk>
- Skills for Care provide practical tools and support for organisations and individuals wanting to employ staff: <http://www.skillsforcare.org.uk>



# Policies: Steering through the acts and policies out there

Blog piece by Liz Wilson

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 so 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 and well as practitioners to give her the chance to make a decision then that's ok.

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. People outside of the immediate family need good information on this too!

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. It took seven years to get an understanding of 'little' and 'now and again' but what a fantastic life lesson that is!

## 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. 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 PA's.

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 be 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. Contraception springs to mind!

### Any decisions I carry out on her behalf should limit her freedoms as little as possible The Mental Capacity Act 2005

I thought about this quite a lot around the money issue. My overall management of my daughter's finances doesn't stop her from making decisions and spending her disposable money as she chooses. It doesn't stop her from making some choices I might think are unwise. She's got a cash-card but I have limited the scope for unscrupulous people to steal from her.

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. The times have long passed when a parent can prevent an adult child with or without learning disabilities from having a sexual relationship. 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.

SEND legislation is essential here. I don't know enough about the new Act to do a coherent summary but you should find info on the PFA website.



# Proving life can get better

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