The Challenging
Behaviour Foundation

making a difference to the lives of people with severe learning disabilities

FAMILY CARER ADVOCACY RESOURCE

www.challengingbehaviour.org.uk Tel. 01634 838739
Registered charity no. 1060714. Registered office: The Old Courthouse, New Road Avenue, Chatham, ME4 6BE.

Contents

The UK Supreme Court has unanimously overruled the 2014 decision in Cheshire West in a significant judgment (UKSC 16, 2 June 2026), we are awaiting updated guidance about how to assess if someone is deprived of their liberty. Therefore some of the information in this resource is out of date and will be updated in due course.

Organisations Involved

The Challenging Behaviour Foundation

The Challenging Behaviour Foundation (CBF) is the only UK charity specifically focused on challenging behaviour associated with severe learning disabilities. We aim to make a real difference to the lives of children, young people, and adults with severe learning disabilities and those who care for and support them. Our overarching objective is to ensure carers and people with a learning disability have access to the right support in the right place at the right time to enable them to live a full, healthy, and active life. We do this by combining the direct lived experience of the families we support with strategic influencing work by:

- Providing information and support to ensure family and professional carers are supported to feel confident in their role as carers, look after their own wellbeing and be strong advocates for the person they support
- Representing and encouraging the voice of families at an individual, system-wide and
- national level through a strategic influencing approach to ensure policy and best practice reflect lived experience and provides robust and practical guidance
- Working in partnership and engaging with professionals and other stakeholders to inform, develop, demonstrate and share best practice to ensure local areas and services are well informed and equipped to meet the needs of people with a severe learning disability

https://www.challengingbehaviour.org.uk

The Advonet Group

The Advonet Group has over 20 years expertise in delivering high quality advocacy and developing innovative user led services. Our staff and volunteers reflect our diverse communities and bring skills and lived experience that enhance our services.

Our Vision

People having their voices heard and taking greater control over their lives, no longer marginalised.

Our Mission

Enabling people to better communicate their needs, understand their choices and obtain their rights.

Our Approach

- Empowering clients, communities and
- colleagues
- Increasing inclusion and challenging where needed
- Demonstrating integrity and accountability
- Building alliances with marginalised communities
- Openness to challenge about what we can do better, celebrating our successes

https://advonet.org.uk/

Pathways

Pathways Associates CIC is based in the North West with members across the UK, we are committed to supporting individuals take control of all aspects of their lives as described by the 12 pillars of independent living. Pathways operates as a social enterprise reinvesting surplus into supporting research and developments which promote our principles and enable us to support people who may be entitled to health and social care services and their families.

https://www.pathwaysassociates.co.uk/

Bringing Us Together

Bringing Us Together works with family members and disabled people to offer a warm and welcoming place to share ideas, stories and our challenges. We hold regular Zoom sessions on a wide range of topics, run workshops and training programmes, offer peer support and keep people updated with information and resources. We work alongside many other organisations putting the voices of families, disabled young people and adults at the forefront of all we do.

https://bringingustogether.org.uk

Cloverleaf

Cloverleaf Advocacy is an independent charity, and all our services are free and confidential for those who need us. We know our stuff too. We've been around for 25 years and have a team of more than 100 highly-trained advocates available to help people across the North of England. Although we're not part of the NHS or social care services, we do understand how they work. We can help people to:

- Find information
- Understand and uphold their rights
- Consider their options
- Get the support they need
- Speak up about the issues that matter to them

https://cloverleaf-advocacy.co.uk

Warrington Speak Up

Warrington Speak Up is an independent advocacy organisation based in the Northwest. We are commissioned to deliver a range of statutory and non-statutory advocacy services, including Care Act Advocacy, Independent Mental Health Advocacy, Independent Mental Capacity Advocacy, Parent Advocacy, Advocacy for Informal Patients, Early Help Advocacy and most recently advocacy for people living with dementia. Our advocacy services are free, independent, confidential and person-led. In addition, Warrington Speak Up is highly regarded in its delivery of creative and bespoke community-based consultation and participation initiatives, self-advocacy groups and low level, non-clinical mental health projects.

We strive for excellence in all that we do whilst remaining committed to knowing well the communities we work within and in understanding the needs of our local population. People are at the heart of both the organisation and the services we deliver.

We believe in, and actively promote a society that is inclusive, celebrating who people are and valuing the contributions they make.

We believe that everyone regardless of their situation, needs or disability, has a right to be heard and respected, to have choice, control and freedom over their lives and to be safe from discrimination, harm and abuse.

https://www.warringtonspeakup.org.uk/

Foreword: Margaret Kitching

Hello! My name is Margaret Kitching and thank you for giving me the opportunity to write this forword.

I am a nurse and while my current role means that I am no longer hands on with patients on a daily basis, I still use the guiding principle of including family carers and relatives in whatever I do. Like most of you reading this, I have many other roles, including being a mum and an auntie to an adult niece who has a severe learning disability and autism. I bring my experience of both these roles to my day-to-day work. The importance of a family carer must never be underestimated and advocating on behalf or alongside their relative regardless of whether it is as a parent, sibling, or other relationship, is so important. Family carers are in a unique position, they have been there for their loved one's entire journey. Their input may have led to a diagnosis being sought and they will have been there for every part of their journey, for example, securing appropriate education, a successful transition from children to adult's services and to accessing the right support to ensure an ordinary life for their relative in the community. Family carers have invaluable knowledge such as their relative's individual way of communicating, what a particular behaviour means, and how their relative responds when they are unwell – physically or mentally. This is recognised in law, for example if a person with a learning disability, autism or both needs somebody to advocate on their behalf they have a statutory entitlement to an Independent Mental Capacity Advocate only if there is no family member or friend available. Despite this, family carers still find themselves fighting to be involved as equal partners in their relative's care - it is therefore so important that family carers are provided with information about their rights, and the rights of their relatives. I have personally been involved in Rosemary and her son's journey. Although there have been challenges along the way, never once has Rosemary's commitment waivered. Her strength and tenacity helped to drive her son's discharge from a mental health service back to an ordinary life in his community. What struck me with this specific case is how Rosemary had to independently learn about her rights as a family carer and those of her son. Often, the information came from other family carers and very rarely from the health and social care professionals supporting her and her son. We must ensure that family carers have access to the right information at the right time in a way that is accessible. I hope that by bringing together the relevant information in this resource, family carers will be able to access information about their rights and those of their relative. I never underestimate the challenge of being a family carer; the lifelong fight to achieve what is best for your relative. I hope this resource goes some way to giving family carers the information and confidence to support you when advocating for your loved one

A family carer's story

Rosemary's Lived Experience of Statutory Advocacy

I am the proud Mum of a fine young man called James who is 28 years old. He has severe autism, a learning disability and other complex needs which means he can, when distressed display behaviours that can most definitely be described as challenging. I have fought his corner for decades to do whateverI could to make his quality of life better and asking me not to do this would be like asking me not to breathe.

James received zero transition planning from children to adult services and a total lack of adequate support resulted in him being sectioned under the Mental Health Act and placed in a local Assessment and Treatment Unit. The premise originally was for it to be a 28 day assessment of need to set him up for his adult life. That 28 day assessment turned into 5 ½ terrible years.

My first experience of statutory advocacy happened when James was injured during a floor restraint. James had never experienced restraint and punitive regimes in his life. In fact I recall having to ask what the term "restraint" meant, it was totally alien to me. Needless to say I quickly learnt as my son went on to be restrained on an almost daily basis. These prone restraints would last hours and after one such episode my son's front two teeth were broken. He hadn't even had a filling up to that point in his life. After this episode there was the first of a great many safeguarding referrals and an advocate/IMHA got involved.

The IMHA was funded by the placing authority and represented the majority of patients on the ward. She set up a meeting with my son's legal representative and invited me along. I arrived and met the solicitor but was asked to leave the meeting before my son came in. The reason I was given for this was my son was 18 now and had his own right to represent himself. I protested that due to his complex needs he wouldn't be able to express himself and would get very distressed, but I was quoted policy again and James was brought into the meeting with 2 bank workers, the advocate and the solicitor who he hadn't met before. None of them had any understanding of his communication difficulties.

A Serious Case Review was later published into my son's abusive care which revealed a staggering number of safeguarding referrals in that hospital alone. Some I had been told about, some I had not. None of these ever resulted in a positive outcome for James. It was my experience that as long as policy and procedures were followed that was all anyone cared about. I found it completely overwhelming to attend a meeting with a large group of professionals all with impressive titles sometimes 13 or 14 people and just me, I rarely was ever called by my name simply referred to as "Mum". I am a gentle non confrontational person by nature, but I was regarded as difficult and demanding because I couldn't sit quietly and watch them destroy my son

At 19 years my son was sent to a Castlebeck Hospital 100 miles from home. It was supposed to be an autism specific service. I enquired before he went about advocacy and this time it was funded by the provider so hardly "independent". This advocate represented every patient at the hospital, and she told me she had very little to do with families as it was an "adult service". This advocate did not warn me when I spoke to her about the serious safeguarding enquiry that was on-going at this service that had stopped admissions, that was only revealed to me years later via the Serious Case Review.

I decided that because this was after Winterbourne View to employ a local independent social worker to be the advocate for James and the family. He successfully visited James every fortnight and he built up a rapport with him and was welcomed but suddenly after 6 months he was "banned ". A week previously he had made a safeguarding referral to the placing authority about lengthy floor restraints. This ban from the hospital came under the pretense that this man couldn't advocate for James and the family despite there being no conflict and that he lacked capacity to consent to this man visiting. This hospital later got my son arrested and on the same day removed his autism diagnosis and told police he was *"culpable and needed to be dealt with".*

Whilst all this turmoil was happening I became an Expert by Experience for the CBF when they were responsible for recruiting and training family carers to participate in CQC Inspections. The knowledge and contacts I gained from that role changed the dynamics completely. My instincts were right………. There was another way other than over medication, restraints and seclusion…………..I learned about Person Centred Plans, Positive Behaviour Support and Trauma Informed Care and what should be happening for my son and those like him James was then sent to a third hospital where thankfully they knew how to support his complex needs. They worked closely with us - his family - and other external organisations. The advocate in this hospital simply told the Ward Manager that he couldn't represent James as James couldn't give him his instructions. He recommended an IMCA for James, but she wouldn't get involved as James had a parent who was willing to speak up for him.

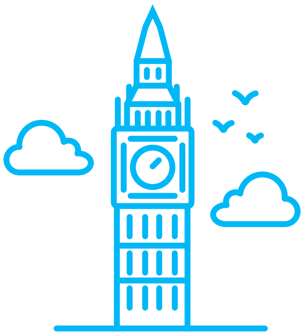
I applied to be James's Health and Welfare Deputy and eventually after appointing a Solicitor and Barrister at the cost of £5,000 I won on appeal at the Court of Protection in London. Every professional attached to James's case supported my application and I now could no longer be excluded as I had a legal right to speak up for my son.

This brought about positive, genuine, partnership working and discharge planning between NHS England, every professional, family, friends, a housing association, solicitors and it included involving a local self-advocacy group being commissioned to facilitate a Person-Centred Plan. All of this happily resulted in my son now living for 5 years in his own self named "magic" house with zero restraints or restrictive practices. He says he is "as free as a bird"!!

At the end of James's 5 1\2 years of detention I too had gained several more titles, "Expert by Experience", "Human Rights & Disability Campaigner", "Keynote Speaker", "Health & Welfare Deputy", "Property & Finance Deputy", "Nearest Relative", and "Litigation Friend" but I believe it should not have been THAT difficult. It would have made such a profound difference to be respected for the most impressive title of all………

James's Mum

What is an Act of Parliament?



An Act of Parliament creates a new law or changes an existing law. An Act is a Bill that has been approved by both the House of Commons and the House of Lords and has been given Royal Assent by the Monarch (the King).

What is a Green Paper?

A Green Paper is the first step towards creating a new law. Its purpose is to allow and start a debate (discussion) without committing to any specific action. Stakeholders (any interested parties) and the public will be invited to comment on the Green Paper. Each Green Paper will contain several alternative policies, which will be discussed before a final decision is made.

What is a White Paper?

A White Paper is the policy document produced by the Government that sets out their proposals for future legislation (e.g. an Act/new law). A White Paper may include a draft version of a Bill (Act) that is being planned. This provides a basis for further consultation and discussion with interested or affected groups and allows final changes to be made before a Bill is formally presented to Parliament. An example is the Valuing People White Paper.

Watch this video summarising the stages involved in making a law

Read how the National Autistic Society, along with other charities, autistic people and their families campaigned for the Autism Act

Read about the development of the British Sign Language Bil

All our information sheets are available to download free of charge because we believe that money should not be a barrier to getting the information you need when you need it.

Please see the end of this information sheet for details of how to support us.

We want to make sure our resources are helpful. Please spend a few minutes giving us some feedback: Feedback form

Putting an Act into force

The Government are responsible for bringing new laws into force once they have been passed by Parliament.

An Act may come into force immediately, on a specific future date, or in stages. Sometimes a specific date is not given, and the timing is decided by the Secretary of State for the relevant government department.

Although Parliament is not responsible for implementing legislation, its committees can investigate how well an Act is being implemented by the Government and the effect that the new law is having. This is known as post-legislative scrutiny.

Changes to Acts

Changes to the law happen through the passing of another Act or delegated legislation. An Act can also be repealed (cancelled) so that its provisions no longer apply. Parliamentary committees examine UK laws and recommend the removal of out-of-date legislation.

Even when reforms (changes) to a law, particularly complex laws, have been passed by Parliament they can take a long time before they are fully implemented in practice.

Changes to Acts may be welcomed by stakeholders (interested parties) and the public, for example the Mental Health Act reforms.

However, the proposed changes to the Human Rights Act were not welcomed by all stakeholders and the public

Read how the British Institute of Human Rights campaigned to ensure that people's human rights were not reduced in any way

Some Acts (laws) affect everyone in society e.g. The Equality Act but there are others which are in place to specifically protect and support people with a learning disability, autism or both e.g. The Autism Act.

Key Message

Knowing about the Acts (laws) relevant to your relative will help you advocate on their behalf to ensure their rights are upheld. You do not have to have an in-depth knowledge of the Acts (laws) but knowing they exist and that they apply to your relative provides an opportunity to raise a concern or make a complaint when the law is not being followed.

How to access Acts

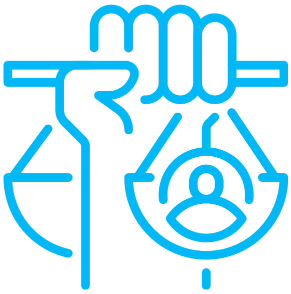
Most current Acts of Parliament are available to read on the legislation.gov.uk website.

Read how the Challenging Behaviour Foundation used this opportunity to further the campaign to change the use of mental health services for people with a learning disability, autism or both

Human Rights Act

Human rights are the basic rights and freedoms that belong to every person in the world

This section of the Family Carer Advocacy Pack outlines the legal basis of human rights in the UK (the Human Rights Act), the rights that this Act protects, along with examples and resources for how the Act should work to protect your relative's rights in health and social care.



The European Convention on Human Rights (ECHR) protects the human rights of people in countries that belong to the Council of Europe. (This is different to the European Union (EU) so although the UK has left the EU, the ECHR still applies.) It is an international human rights agreement established between members of the Council of Europe, including the UK. It brings rights within the ECHR into UK domestic law and protects everyone in the UK, no matter what their nationality or immigration status is.

A bill was being proposed by the government to change the Human Rights Act to the Bill of Rights. There were major concerns about how this new law would reduce people's rights. Through campaigning, the government has now [decided not to pursue the Bill of Rights](#).

Key Message

Knowledge of the Human Rights Act and its individual articles will ensure you can identify if the care and support and/or treatment your relative receives breaches their rights (when the law is broken) and what you and/or your relative can do to resolve this. The Human Rights Act is being used more and more by people with a learning disability, autism or both and their family carers to successfully challenge poor care and support and/or treatment when other ways have failed. If your human rights are breached you can use the Act to take action by raising a concern or making a complaint to the relevant organisation or you may be able to seek justice in the UK courts

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The Act sets out your human rights in a series of 'Articles'. Each Article deals with a different right. These are all taken from the European Convention on Human Rights and are commonly known as 'the Convention Rights'

Article 2:	Right to life (absolute)
Article 3:	Freedom from torture and inhuman or degrading treatment (absolute)
Article 4:	Freedom from slavery and forced labour (absolute)
Article 5:	Right to liberty and security (non-absolute)
Article 6:	Right to a fair trial (absolute)
Article 7:	No punishment without law (absolute)
Article 8:	Respect for your private and family life, home and correspondence (non-absolute)
Article 9:	Freedom of thought, belief and religion (part absolute/non-absolute)
Article 10:	Freedom of expression (absolute)
Article 11:	Freedom of assembly and association (absolute)
Article 12:	Right to marry and start a family (non-absolute)
Article 14:	Protection from discrimination in respect of these rights and freedoms (non-absolute)
Protocol 1, Article 1:	Right to peaceful enjoyment of your property (non-absolute)
Protocol 1, Article 2:	Right to education (absolute)
Protocol 1, Article 3:	Right to participate in free elections (non-absolute)
Protocol 13, Article 1:	Abolition of the death penalty (absolute)

Absolute rights (like the right not to be tortured) apply in all situations without exception and cannot be restricted in any way.

Non-absolute rights (like the right to liberty) can be restricted in certain circumstances as specified in the relevant Article of the European Convention on Human Rights. For example, if a person is convicted and sentenced to prison.

Whenever a non-absolute right is restricted, this restriction must be:

- Lawful (there is a law allowing it)
- Legitimate (there is a genuine aim or reason for doing it)
- Proportionate (it is the least restrictive way to meet that aim)

The Act applies to:

- All public authorities such as central government departments, local authorities and NHS Trusts,
- And all other private bodies performing functions such as delivering publicly funded care (e.g. independent mental health hospitals) and prisons

5 rights in the Human Rights Act that are important in health and care

Right to life

Protection from discrimination

Right to freedom from torture and inhuman or degrading treatment

Right to liberty

Respect for your private and family life

The Human Rights Act can be summarised under five core principles using the acronym (abbreviation) FREDA which stands for:

F **Fairness**

R **Respect**

E **Equality**

D **Dignity**

A **Autonomy**

These principles protect you in your everyday life regardless of who you are, where you live and how you choose to live your life.

Read how CQC use the Human Rights Act to support the regulation of services and inspection process

This video by the Health Information and Quality Authority shows what these principles mean in Health and Social Care

Article 2 of the Act protects your right to life

This means that nobody, including the government, can try to end your relative's life. Public authorities should consider your relative's right to life when making decisions that might put them in danger or that affect their life expectancy. Examples of where there could be a breach of Article 2 include:

- If someone dies because of negligence/neglect, for example in a hospital or care home
- If someone is refused life-saving treatment
- Refusal to investigate a death caused by a public authority

If someone is killed by a public authority or dies because a public authority has failed to protect their life, the state has a duty to investigate the death

Watch this video about Article 2, co-produced by the British Institute of Human Rights and Mencap Liverpool

Article 3 protects your right to be free from torture and inhuman or degrading treatment

- Torture (mental or physical) occurs when someone deliberately causes very serious and cruel suffering (physical or mental) to another person. This might be to punish someone, or to intimidate or obtain information from them.
- Inhuman treatment or punishment is treatment which causes intense physical or mental suffering. It includes:
  - serious physical assault
  - psychological interrogation
  - cruel or barbaric detention conditions or restraints
  - serious physical or psychological abuse in a health or care setting
  - threatening to torture someone, if the threat is real and immediate
- Degrading treatment means treatment that is extremely humiliating and undignified. Whether treatment reaches a level that can be defined as degrading depends on a number of factors. These include:
  - the duration of the treatment
  - its physical or mental effects
  - the sex, age, vulnerability and health of the victim

Public authorities must not inflict this sort of treatment on your relative. They must also protect your relative if someone else is treating them in this way. If they know Article 3 is being breached, they must intervene to stop it and also investigate any allegations of such treatment.

Watch this video to see an example of how the Act was used to challenge Susan's treatment

Article 4 protects your right not to be held in slavery, servitude, or to be made to do forced labour

This right protects you against:

- Slavery (when someone actually owns you like a piece of property)
- Servitude (similar to slavery - you might live on the person's premises, work for them and be unable to leave, but they don't own you)
- Forced labour (forced to do work that you have not agreed to, under the threat of punishment)

This right can be used to protect your relative if they are being made to work for nothing or an illegal wage, either against their will or unknowingly.

For more information on Article 4 read this resource

Article 5 protects your right to liberty and security

It aims to protect people's freedom from unreasonable detention. Your relative has a right to personal freedom. This means they must not be imprisoned or detained without good reason. If arrested, the Act says that you have the right to:

- Be told in a language you understand why you have been arrested and what charges you face
- Be taken to court promptly
- Bail (temporary release while the court process continues) subject to certain conditions
- Have a trial within a reasonable time
- Go to court to challenge your detention if you think it is unlawful
- Compensation if you have been unlawfully detained

Are there any restrictions to this right? In certain circumstances public authorities can legally detain you relative, for example if they:

- Have been found guilty of a crime and sent to prison
- Have not done something a court has ordered them to do
- Are under suspicion of committing a crime, someone is trying to stop them committing a crime, or they are trying to stop them running away from a crime
- Have a diagnosed mental health condition which makes it necessary to detain them

Read this well-known case study

Steven, a young autistic man, needed temporary care while his dad (Mark) was unwell. Mark assumed Steven would stay at his usual respite care home, but the local council placed Steven in a specialist unit because of concerns about his behaviour. Mark expected this to be a temporary move and for Steven to be home again within weeks. When the council insisted on keeping Steven in the unit for longer, Mark challenged this decision. Steven had been detained in the unit for almost a year when the Court of Protection (a specialist court at the High Court which deals with issues concerning people who have been assessed as lacking the mental capacity to make decisions for themselves) ruled that the council had breached his Article 5 rights and unlawfully deprived him of his liberty. The court order enabled Steven to return home.

(Re Steven Neary; LB Hillingdon v Steven Neary (2011) EWHC 1377 (COP))

Watch this video of Steven and Mark Neary

Article 8 protects your right to respect for your private life, your family life, your home and your correspondence (letters, telephone calls and emails)

What is meant by private life?

Your relative has the right to live their life privately without the government interfering, including the right to determine their sexual orientation, lifestyle, and the way they choose to look and dress. It also includes your relative's right to control who sees and touches their body. This means that public authorities cannot do things like leave your relative undressed in a busy ward, or take a blood sample without consent. The concept of private life also covers the right to develop a personal identity, friendships and other relationships. This includes a right to participate in essential economic, social, cultural and leisure activities. Your relative may require support to exercise this right, for example from support staff to help them access their local swimming pool.

What is meant by family life?

Your relative has the right to enjoy family relationships without interference from government. This includes the right to live with their family and, where this is not possible, the right to regular contact. ('Family life' can include the relationship between an unmarried couple, an adopted child and adoptive parent, and a foster parent and fostered child.)

Visit the BIHR page for more information about Article 8 Right to respect for private and family life, home and correspondence. If you scroll down you can read Nina's story which is about a young woman who was moved from a mental health service 200 miles from home. Nina's IMHA advocate used Article 8 to argue for a move closer to home and this was successful without the need to go to court. Read more or watch this video

People with learning disablities, autism or both are entitled to develop and have intimate relationships just like everyone else. it is a basic human right, but they often face barriers.

What is meant by home?

The right to respect your home does not give you a right to housing. It is a right to enjoy your existing home peacefully. This means that public authorities should not stop you from entering or living in your home without very good reason and they should not enter without your consent. This applies whether or not you own your home.

Watch this video which was part of research carried out by NDTi looking at the barriers people with a learning disability, autism or both can face. Read more or watch this video

Are there restrictions to this right?

There are situations when public authorities can interfere with your relative's right to respect for private and family life, home and correspondence. This is only allowed where the authority can show that its action is lawful, necessary and proportionate, for example to:

- Protect public safety
- Prevent disorder or crime, or
- Protect the rights and freedoms of other people

There's no place like home: the right to respect for private life and home in social care:

Article 14 requires that all of the rights and freedoms set out in the Act must be protected and applied without discrimination

Discrimination occurs when you are treated differently compared to another person in a similar situation and this treatment cannot be fairly and reasonably justified.

Discrimination can also occur if you are disadvantaged by being treated the same as another person when your circumstances are different (for example people with a learning disability, autism or both). The act does not protect you from discrimination in all areas of your life. There are other laws that you can rely on to be treated fairly such as the Equality Act 2010

What type of discrimination does the Act protect you from?

The Human Rights Act makes it illegal to discriminate on a wide range of grounds including sex, race, colour, language, religion, birth or other status. The term 'other status' includes sexual orientation, illegitimacy, marital status, transsexual status, language and religion. It can also be used to challenge discrimination based on age or disability.

Does the right cover indirect discrimination?

The courts have also ruled that the human rights protection from discrimination includes indirect discrimination. This happens when a rule or policy, supposedly applying to everyone equally, works to the disadvantage of one or more groups. For example, if an organisation has a requirement that all employees must be able to drive. People with a learning disability, autism or both may be disadvantaged. To be justified being able to drive would need to be a strict requirement for the job, e.g. a bus or delivery driver.

The Human Rights Act and Advocacy

Share this link with your relative for all the British Institute of Human Rights easy read resources including postcards co-produced with Warrington Speak UP

Read how the postcards were developed here

Professional Independent Advocates

The term 'rights-based approach' is a phrase used by professional independent advocates to confirm that when they are advocating on behalf of someone they always ensure that the Human Rights Act is being upheld.

Read this article including a section on ‘How can human rights be used in advocacy’

This case study from the Advonet Group demonstrates how Article 8 Respect for your private and family life, home and correspondence and Article 9 Freedom of thought, belief and religion was used successfully to allow the person they were representing to celebrate a cultural festival, important to them, with their family

Further information

The British Institute of Human Rights

The main source of information for this section is from the British Institute of Human Rights.
https://www.bihr.org.uk/

This document includes a flow chart to help family carers identify whether their relative’s human rights are at risk
https://knowyourhumanrights.co.uk/resources/Learning%20Disability,%20Autism%20and%20Human%20Rights%20Accessible%20Resource%20HighRes.pdf

If the answer is yes, you can use this template letter to formally raise this
https://knowyourhumanrights.co.uk/wp-content/uploads/2019/05/KYHR-letter-template-FD.pdf

Although this resource has been developed for refugees, it includes information which is relevant to everyone and includes useful template letters, e.g. how to formally raise concerns about somebody’s human rights, it has information about how to follow through a concern, e.g. what to do if you do not receive a response or are not satisfied with a response.
http://drive.google.com/drive/folders/1x-e0hTTCINMQPlo1pkgW9vtFUcSP1JBF

This BIHR resource summarises the Human Rights Act in an easy read format
http://www.bihr.org.uk/media/lh0hk4cm/easyreadhra.pdf

Equality and Human Rights Commission

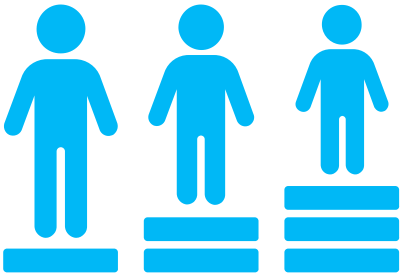
Visit the Equality and Human Rights Commission website for more information including case study examples https://www.equalityhumanrights.com/en

Equality Act 2010

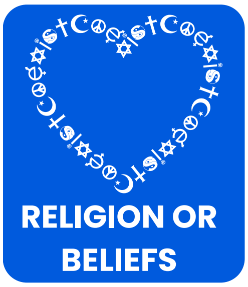
This section of the Family Carer Advocacy Pack is about the Equality Act 2010, the characteristics it covers, different types of discrimination and reasonable adjustments.

What is the Equality Act 2010?

The Equality Act 2010 is a legal framework which seeks to eliminate discrimination, ensure equality of opportunity, promote good relations between people who share a 'protected characteristic' and prevent harassment and victimisation.



There are 9 protected characteristics and it is against the law to discriminate against someone because of any of these.



Watch this video from the Equality and Human Rights Commission:

All our information sheets are available to download free of charge because we believe that money should not be a barrier to getting the information you need when you need it.

Please see the end of this information sheet for details of how to support us.

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There are four main types of discrimination

1. Direct discrimination
This means treating one person worse than another person because of a protected characteristic.

2. Indirect discrimination
This means an organisation makes a rule, has a policy or a way of doing things which has a worse impact on a person with a protected characteristic than a person without one.

3. Harassment
This means treating a person in a way that does not respect their dignity, or causes them to feel intimidated or offended.

4. Victimisation
Victimisation means being treated unfairly because you have made a complaint about discrimination personally or you are supporting someone who has experienced discrimination to make a complaint.

Discrimination does not have to be intentional to be unlawful.

Under the Equality Act you are protected from discrimination in the following settings:

- Workplace
- Public services like health and social care (e.g. visiting your doctor) or education (e.g. college)
- Businesses and other organisations that provide services and goods (e.g. shops, restaurants, and cinemas)
- Public transport
- Clubs or associations
- Public bodies (The Equality Act requires public bodies e.g. local authorities, hospitals, and publicly funded service providers to think about how their decisions and policies affect people with different protected characteristics and need to provide proof to show how it has done this.)

One of the protected characteristics is disability. The Equality Act 2010 defines disability as having a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities.

The Equality Act and reasonable adjustments (changes)

The Equality Act recognises that ensuring equality for disabled people means:

- Changing the way in which services are delivered
- Providing extra equipment and/or
- The removal of physical barriers

This is the 'duty to make reasonable adjustments'. A duty is something that must happen, in this case because it is the law.

The duty is 'anticipatory'. This means an organisation must not wait until a disabled person wants to use its services but instead think in advance (and on an ongoing basis) about what disabled people might reasonably need.

We come across anticipatory reasonable adjustments daily, without even recognising them, for example:

- Pedestrian crossings with an auditory tone to indicate when it is safe to cross for people who have a visual impairment
- A portable induction loop for people with a hearing impairment
- Wider doorways and lifts for people with a mobility impairment

- Information in easy read for people with a learning disability
- Quieter shopping hours in supermarkets, when the lights are dimmed and the music is turned off for autistic people

If an organisation has achieved the Advocacy Quality Performance Mark for equality, diversity and accessibility, here is what it should have in place:

- An up to date Equality and Diversity Policy that meets the requirements of current legislation and recognises the need to be pro-active in tackling all forms of inequality, discrimination and social exclusion so that everyone is treated fairly
- Procedures to ensure that any issues or complaints regarding equality and diversity are resolved effectively and in a timely fashion
- Equality and Diversity training and the impact of this is checked e.g. during supervision/ appraisals
- Advocates' time is allocated equitably
- Reasonable adjustments
- Policies, procedures, and publicity materials promote full access for the people who use its service.
- Information and language that is easy to understand and accessible.
- Accessible premises or the use of accessible meeting spaces that create a welcoming environment for all.
- Opening hours that are accessible for the people who want to use or refer to the service.
- A contingency plan to ensure a service is still available during periods of staff illness or holiday.
- A free service if people are entitled and if the organisation is funded directly to provide this service.

Further information

Read the government's guidance about the Equality Act 2010:
http://www.gov.uk/rights-disabled-person

Explore the Disability Rights UK website and the Right to Participate website which also includes examples of how people have used the Equality Act to challenge discrimination, harassment, and victimisation:
http://www.disabilityrightsuk.org/resources/equality-act-and-disabled-people

http://stories.righttoparticipate.org/stories/?page=3

Information about carers rights under the Equality Act: http://www.carersuk.org/help-and-advice/work-and-career/protecting-yourself-from-discrimination/

Leaflet "Equality Act 2010: What do I need to know as a carer?":
http://www.equalityadvisoryservice.com/ci/fattach/get/585/1354033248/redirect/1/session/L2F2LzEvdGltZS8xNjYwNTgzOTQ2L3NpZC90NUQzMUhNcA==/filename/carers.pdf

Mind provides information about 'Discrimination in everyday life' including the type of discrimination people with a mental health condition may experience and the solutions which should be offered:
http://www.mind.org.uk/information-support/legal-rights/discrimination-in-everyday-life/overview/

Mental Capacity Act 2005

This section of the Family Carer Advocacy Pack covers what you need to know about the Mental Capacity Act 2005 (MCA) if you are a family carer and your relative is approaching the age of 16 years old and you have been making decisions on their behalf.

What is the Mental Capacity Act?

The Mental Capacity Act is a law that says that anybody aged 16 years old and over regardless of whether they have a learning disability, autism or both, has the right to make their own decisions wherever possible. It covers day-to-day decisions like what to wear or what to eat for lunch and serious life-changing decisions like whether to have surgery. If your relative is assessed as not having the capacity to make a specific decision at a specific time, then a best interests process must be followed.

Are there any decisions not covered by the Mental Capacity Act?

There are certain decisions that cannot be made for another person under Mental Capacity Act law. This is because the decision is either so personal to the individual concerned, or because it is governed by other legislation. Decisions that cannot be made under the Mental Capacity Act law include:

- Consenting to marriage or a civil partnership
- Consenting to sex
- Consenting to a child being placed for adoption
- Voting at an election

There is a Mental Capacity Act Code of Practice which explains the Mental Capacity Act 2005 in detail. There is a duty under the Act for all organisations and individuals (e.g. doctor, nurses, social workers and paid support staff) to consider the code at all times if they have a responsibility for making decisions when a person had been assessed as lacking the mental capacity to do so themselves.

[Click here to read the Mental Capacity Act Code of Practice]

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The MCA sets out 5 core principles:

5 rules for supporting me

1. Start by thinking I **can** make a decision
2. Do **all** you can to **help** me make a decision
3. You must **not** say I lack capacity just because my decision seems unwise
4. Use a **best interest checklist** for me if I can't make a decision
5. Check the decision made **does not** stop my freedom more than needed

1. Presumption of mental capacity (the ability to make a decision and understand the consequences of that decision).

We should never assume that just because a person has a learning disability, autism or both that they lack capacity to make decisions. A lack of capacity cannot be determined solely by a person's age or appearance, diagnosis or an aspect of their behaviour, which might lead others to make unjustified assumptions about the person's capacity. Capacity changes over time for all of us. For example if a person has been unwell recently their ability to make decisions may be impacted. Where possible, major decisions should be postponed until the person's circumstances and ability to take part in the decision-making process improves

2. People must be supported to make decisions.

Information should be given in a way that makes sense to the person. A person may also require support from a family carer, other family member, friend or support worker to help them.

Click here to watch the video from Infodeo on the Mental Capacity Act

Click here to watch the video from the Social Care Institute for Excellence on the Mental Capacity Act

Helping people make their own decisions

Before deciding a person lacks capacity, it is important to take steps to enable them to try and make the decision themselves.

For example:

- Does the person have all the relevant information they need?
- Have they been given information on any alternatives?
- Could information be explained or presented in a way that is easier for them to understand?
- Have different methods of communication been explored, such as non-verbal communication, e.g. sign, talking mats, social story?
- Could anyone else help with communication, such as a family carer, other family member, friend, support staff or independent professional advocate?
- Are there particular times of day when the person's understanding is better?
- Are there particular locations where the person may feel more at ease?
- If the person is usually able to make decisions independently but their current circumstances (e.g. illness) are preventing this, can the decision be delayed until they are back to their usual self?

Watch this video from SCIE showing how a young man was supported in a person-centred way to be involved in a decision about moving house

3. Unwise decisions do not necessarily mean a lack of capacity. A person has the right to make an unwise decision. The purpose of a capacity assessment is to determine a person's ability to make a decision, not to make a value judgement on their decision.

4. Decisions must be taken in a person's best interests. This is a difficult concept. It means putting yourself in the person's shoes. Past decisions and knowledge of what is important to the person are important considerations during this process. Everyone involved should imagine what the person would choose if they did have capacity.

5. Consider how a decision can be made in a way that is the least restrictive.

Consider this example of good practice:

Eddie's mobility has recently deteriorated, and he is struggling to get up and down the stairs. An assessment found that even with support he lacks the capacity to understand his changing health needs and ability to manage stairs. However he was able to indicate that he did not want to move house.

A best interests process was followed, and the options discussed were:

- The least restrictive option would be to adapt the home by fitting a stair lift or moving Eddie downstairs
- The most restrictive option would be to decide that Eddie should move home.

What does the Mental Capacity Act mean for family carers?

If your relative cannot make all their own decisions after they turn 16 years old, you can continue to make some decisions for them in their best interests. However, you cannot automatically do this for them in all aspects of their life. Other people may need to be involved in the decision-making process, e.g. if it is a medical decision, this will be a doctor. Anyone making a best interest decision on behalf of a person who has been assessed as lacking capacity **must consult with the person's family carer, other family members and friends and take their views into account.**

Watch this video from Hft about involving family carers

The least restrictive option should always be chosen, where possible

These 5 core principles must be considered and followed in every instance when working with someone who has been assessed as lacking capacity to make a decision for themselves.

How is mental capacity assessed?

There is a two-stage test to decide if someone lacks mental capacity.

Stage one: Does the person have an impairment of, or a disturbance in the functioning of, their mind or brain? This could include people with a learning disability, autism or both.

Stage two: Does the impairment mean the person is unable to make a specific decision when they need to? People can lack capacity to make some decisions but have capacity to make others. Mental capacity can also fluctuate with time.

Someone may lack capacity at one point in time but may be able to make the same decision at a later point in time. This is why a capacity assessment should only ever relate to a specific decision at a specific time.

The same 2 stage test applies for every assessment of mental capacity. However the nature of the information and steps will vary depending on:

- The person's needs
- The nature of the decision to be made
- The urgency with which the decision needs to be made
- The impairment or disturbance does not have to be diagnosed but a judgement must not be made solely based on:
  - the person's age
  - the person's outward appearance
  - any physical disability or sensory impairment
  - the person's behaviour (including making an unwise decision)

What is the point of doing a mental capacity assessment?

The purpose of any capacity assessment is not to judge the decision a person makes but to determine whether a person is able to make the decision. Section 3 of the Mental Capacity Act says that a person is able to make their own decision if they can do all of the following 4 things:

1. Understand the information relevant to the decision
2. Retain that information long enough to be able to make the decision (if only for a short amount of time)
3. Use or weigh up that information as part of making the decision
4. Communicate the decision (whether verbally, using sign language or any other means of communication, e.g. talking mats)

Who assesses mental capacity?

For day-to-day decisions, e.g. what to wear, whoever (e.g. family carer, paid support staff) is involved with the decision because they are providing care and support/and or treatment is the one who would assess mental capacity. If the decision is a complex one e.g. whether to have surgery, move house, then a professional opinion might be necessary, for example the opinion of a hospital consultant, psychologist, social worker. For complex decisions there is a process which should be followed, including:

- A formal record of the assessment should be recorded as soon as possible after it has been carried out
- The record must demonstrate that the statutory principles of the Mental Capacity Act have been applied and each element of the functional test assessed
- The record should contain all of the following:
  - The evidence that has been used to confirm the presence of an impairment or disturbance of the mind or brain
  - The decision to be made
  - The relevant information that has been provided to the person
  - The steps that have been taken to support the person to make their own decision
  - The outcome of each element of the functional test of capacity
  - The reason that the person has been deemed to lack capacity, that consideration has been given to delaying the decision, if they are likely to regain capacity

Notifying Others

The following people should be notified of the outcome of the assessment:

- The person who lacks capacity
- Any representative of the person e.g. family carer, other family member or friend
- Any Lasting Power of Attorney or Court Appointed Deputy
- Anyone that the person has asked to be notified
- Anyone else that it is deemed relevant to notify either with the person's consent or in their best interests if they have been assessed as lacking the capacity to consent

What can I do if I disagree with a mental capacity assessment decision?

If you disagree with a mental capacity assessment decision, for example if your relative is assessed as lacking mental capacity when you think they have mental capacity, there are various ways you can try and resolve this.

- You can raise the matter with the person who carried out the assessment and ask them to give the reasons why they believe your relative lacks the mental capacity to make the decision and ask them to provide objective evidence to support that belief
- You can try and get a second opinion from an independent professional
- If you cannot resolve the disagreement then you may be able to apply to the Court of Protection, who can make a decision as to whether a person has mental capacity

Best Interests Decisions

When somebody is assessed as lacking mental capacity, then any decision made on their behalf should be done in their best interests. This is the case whether the person making the decision is a family carer, another family member, a friend, paid support staff, a lasting Power of Attorney, a Court Appointed Deputy, or a professional independent advocate.

Who makes the best interests decision will depend on the decision and whether there is anyone with the legal right to make the decision. If the decision is an everyday decision, for example if somebody needs support to identify appropriate clothing then the person most directly involved should be the decision maker e.g. a family carer or paid support staff. These types of decisions are not usually formally recorded. For more complex best interest decisions the nominated decision maker e.g. GP, psychiatrist, social worker should consult with:

- Any Lasting Power of Attorney or Court Appointed Deputy. If the Power of Attorney or Court Appointed Deputy does not have the relevant authority to be the decision maker themselves i.e. a Power of Attorney for property and financial affairs should still be consulted about a decision relating to health and welfare
- Family carers, other family members and friends
- Paid support staff
- And anyone else who is interested in the welfare of the person

and there should be a formal record kept of the process and the outcome. The Mental Capacity Act says that when deciding what is in a person's best interests this checklist should be used:

- Encourage participation - do whatever is reasonably possible to permit or encourage the person who lacks capacity to take part or to improve their ability to take part in making the decision
- Identify all relevant circumstances - try to identify all the things the individual assessed as lacking capacity would consider if they were making the decision themselves
- Find out the person's views - including:
    - their past wishes and feelings about the matter to be decided
    - their present wishes and feelings about the matter to be decided
    - any beliefs or values that would be likely to influence the decision in question, e.g. religious
    - any other factors that the person would be likely to consider if they were making the decision or acting for themselves
- Avoid discrimination - do not make assumptions based on age, appearance, condition or behaviour
- Assess whether the person might regain capacity - if this is a possibility, could the decision be postponed

Best Interests Decision Meeting - Good Practice

Keep the person at the centre of the meeting. This is the responsibility of the Chair. Ways to do this include:

- A photo of the person on the agenda
- Having an empty chair in the meeting to represent the person (if it is not appropriate for them to attend)
- A profile of the person which includes their personal history, description of their personality, values, wishes, beliefs, attitudes to health, life goals, religion and spirituality, and the quality of life that is acceptable to them
- During the meeting, regularly asking people to consider what the person would say, for example:
    - Mum/Dad/Friend: what do you feel is most important here? What do you think Yusuf would say?
    - If Melanie was here and for five minutes could fully appreciate all these issues, what would she say about this decision now?

After the meeting consider the best way to communicate the outcome to the person to maximise their understanding of the decision, for example:

- Meeting one-to-one after the meeting
- Asking them to join the meeting at the end
- Using their preferred method of communication which may include a social story, signing, AAC

The British Psychological Society provides information and resources about best interests decision making

Advance Statements and Decisions

An advance statement is a written document that sets out a person's preferences (likes/dislikes), wishes, feelings, values and beliefs about their future care. Although not legally binding, the aim is to provide a guide for anyone who might have to make decisions in a person's best interests if that person has lost the capacity to make decisions or communicate their decision. An advance statement can cover any aspect of a person's future health or social care. This could include:

- Where they would like to live
- How they would like to be supported
- How they like to do things for example, if they prefer a shower instead of a bath, or like to sleep with the light on

Using the principles of an advance statement can ensure that care and support and/or treatment is provided in a person-centred way. For example, if your relative is admitted to an acute or mental health hospital, it is a way of ensuring that staff know what they were like before they became unwell. This can help judge whether the care and support and/or treatment they are receiving is resulting in good outcomes.

The following documents can be used to record this information:

- Communication passport
- Hospital passport
- Health action plan
- Positive behaviour support plan
- Activity schedule
- Person-centred plan
- Support plans for activities

Family Carer Advocate

If your relative is assessed as lacking capacity then you can continue to act on their behalf (e.g. apply for their entitled benefits, contribute to their Care Act assessment) and make some decisions even when they turn 16 years old.

More complex decisions may involve professionals such as a social worker if there is a decision about where your relative lives or a doctor if you relative requires surgery, but they must include you (and your relative).

If you do not wish to represent your relative or there is disagreement, for example between your views and that of a social worker/health care professional, then an independent mental capacity act advocate may become involved

Read this information from the Challenging Behaviour Foundation about being involved in making decisions with or on behalf of your relative

Read more on consenting to healthcare treatment

If you feel that your right to be involved as a family carer is not being upheld use this template letter:

Independent Mental Capacity Act (IMCA) Advocate

If your relative has been assessed as lacking capacity to make a specific decision at a specific time (e.g. about serious medical treatment, or where they live) and does not have a family carer, other family member or friend to represent their best interests they have a statutory (legal) entitlement to an IMCA. An IMCA's role will include:

- Supporting your relative to make/be included in the best interests decision
- Explaining to your relative what is good and bad about the proposed decision
- Trying to identify all of the things that your relative would think about if they were making the decision, e.g. their past and present wishes, feelings, values and beliefs
- Gathering the views of people who know your relative well and are interested in their quality of life
- Using any documents to provide information to those involved in the best interests decision to help work out what is in your relative's best interests
- Represent your relative to those involved in the decision making so that their best interests are known
- Asking questions or challenging decisions that do not appear to be in your relative's best interests

Read more about the role of an Independent Mental Capacity Act Advocate

Read Carol's story

Read this factsheet from Cloverleaf Advocacy

Further information

The Challenging Behaviour Foundation's factsheet 'How do my family member's rights change as they become an adult' includes information about decision making with or on behalf of your relative once they reach the age of 16 years old:

https://www.challengingbehaviour.org.uk/wp-content/uploads/2021/03/7-How-do-my-family-members-rights-change-as-they-become-an-adult.pdf

Read Mencap's Mental Capacity Act Resource Pack:

https://www.mencap.org.uk/sites/default/files/2016-06/mental%20capacity%20act%20resource%20pack_1.pdf

Read these scenarios from Coventry City Council about the use of the Mental Capacity Act/Best Interest Decisions:

https://www.umccoventry.co.uk/case-scenarios-mental-capacity-best-interest-decisions/

Read the Mental Capacity Act - Decision Making Pathway:

https://www.derbyshirehealthcareft.nhs.uk/application/files/3315/7547/2222/appendix_4a-_decision_making_pathway.pdf

Read the Care Quality Commission guidance for health and social care services to check whether they are following the Mental Capacity Act. Within the guidance there is information about the use of restraint and the Mental Capacity Act and the role of Independent Mental Capacity Act advocates.

https://www.cqc.org.uk/sites/default/files/documents/rp_poc1b2b_100563_20111223_v4_00_guidance_for_providers_mca_for_external_publication.pdf

The UK Supreme Court has unanimously overruled the 2014 decision in Cheshire West in a significant judgment (UKSC 16, 2 June 2026), we are awaiting updated guidance about how to assess if someone is deprived of their liberty. Therefore some of the information in this resource is out of date and will be updated in due course.

Deprivation of Liberty Safeguards (DoLS)

The government has started the process of reforms to the Mental Capacity Act Code of Practice. This includes changes to Deprivation of Liberty Safeguards which will be replaced by 'Liberty Protection Safeguards'. This resource will be updated to reflect any changes in the law once they are made.

What is a Deprivation of Liberty Safeguard (DoLS)?

Introduced in 2009 under an amendment to the Mental Capacity Act 2005 (MCA). In 2004 The European Court of Human Rights (ECHR) decided that the legal system did not give adequate protection to people who had been assessed as lacking the mental capacity to consent to their care and support and/or treatment and who needed to be deprived of their liberty. The Human Rights Act Article 5 protects your right to personal liberty and requires safeguards to be provided to those deprived of liberty. DoLS intend to:

- Protect your relative from being detained if it is not in their best interests
- Prevent arbitrary detention when other possible alternatives have not been fully considered
- Provide a legal process for your relative and/ or their representative (this could be you) to challenge the deprivation of liberty

DoLS in a care home or hospital

DoLs can occur in a number of settings including a care home, hospital (mental health and acute), supported living, family or own home.The care home or hospital is known as the Managing Authority (MA). Sometimes, the Managing Authority may think it is necessary to take away some of your relative's liberty (freedom) to provide them with the care and support and/or treatment they need and to keep them safe. The DoLS framework ensures that any deprivation of liberty is legal and must be appropriate, proportionate and in your relative's best interests.

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Examples of DoLS include:

- Regular use of physical restraint or medication (to sedate) to control behaviour
- Use of blanket restrictions
- Being under continuous supervision your relative objects (verbally or physically) to restrictions
- Your relative is confined to a particular area within their accommodation

There are two kinds of DoLS authorisation:

1. An urgent authorisation which is put in place by a care home or a hospital.
2. A standard authorisation which is put in place by a local authority.

Urgent authorisation

In an emergency, or in situations where there is no time to go through the assessment process, a hospital or care home can grant an urgent DoLS authorisation. This is only valid for 7 days and an application for a standard DoLS assessment and authorisation must be completed at the same time. If the assessment has not been carried out within 7 days and the deprivation of liberty is still needed, the urgent DoLS authorisation can be extended for a further 7 days. After 14 days, no further urgent authorisation can be put in place in the same hospital or care home during the same period of admission. A copy of the urgent authorisation must be given to your relative as soon as possible. Your relative should be given a verbal and written explanation about how they can challenge the authorisation by applying to the Court of Protection. If your relative is not able to understand this information, another way of enabling them to exercise their right of appeal must be found. This includes informing a family carer or other family member about the authorisation, or by urgently appointing an Independent Mental Capacity Advocate (IMCA).

Case Study 2

Mike lives in a care home
He will sometimes try to eat inappropriate objects
He is supervised on excursions by two members of staff

MCA: Deprivation of liberty. The Supreme Court judgment in practice

By Social Care Institute for Excellence (SCIE)

Watch this video clip from SCIE, which includes two case studies. The second case study is about a man who has a learning disability and autism. Both case studies show the role of the Human Rights Act when depriving somebody of their liberty. The second case study also explains the role of a professional independent advocate when a DoLS application is made.

Click here to watch the video

The Deprivation of Liberty Safeguards Code of Practice provides more information

Standard authorisation

If a Managing Authority thinks it needs to deprive someone of their liberty, they must seek authorisation up to 28 days before they plan to start the deprivation of liberty. A standard authorisation can last for up to 12 months and can then be renewed for subsequent periods of 12 months. A standard authorisation can only be granted if your relative meets all the following:

[Read more about Article 5 of the European Convention on Human Rights]

- The best interests assessor - usually a qualified social worker, nurse, occupational therapist, psychologists
- The mental health assessor - must be a medical doctor, typically a psychiatrist, who assesses whether your relative has a mental disorder within the Mental Health Act

They are appointed by the local authority (or health board) who make sure that they have the right training and experience.

What does the assessment involve?

There are six parts to the assessment. The assessors (best interests and mental health) will decide whether your relative and the care and support and/or treatment that they receive meet the 'criteria for authorisation' (the rules that allow a person to be deprived of their liberty).

The six parts are:

1. Age – must be aged 18 years or over
2. Mental health – your relative must have a 'mental disorder'
3. Mental capacity – your relative have been assessed as lacking 'capacity' (the ability) to make their own decisions about their care and support and/or treatment. Your relative must still be supported to be involved in the process as much as possible.
4. Best interests – if a deprivation of liberty is to take place it must be:

- In your relative's best interests
- Needed to keep your relative safe from harm
- A reasonable response to the likelihood of your relative suffering harm (including whether there are any less restrictive options and if they are more appropriate)

5. Eligibility – your relative cannot already be detained under the Mental Health Act (1983) or meet the requirements for detention under the Mental Health Act. If they are, the Mental Health Act should apply and not DoLS
6. No refusals – Your relative has not made an advance decision to refuse treatment which conflicts with the care they are being given, and any Lasting Power of Attorney or a Court-Appointed Deputy for Health and Welfare (this could be you) agrees that your relative should be deprived of their liberty

Usually assessors will meet your relative and look at their medical and care and support and/or treatment records.

What if assessors do not allow a deprivation of liberty?

If the assessors decide that the criteria for a DoLS is not met they will tell the local authority or health board the reasons for their decision. The deprivation of liberty will not be authorised, and it should not happen.

What happens next will depend on the reasons why the criteria were not met. For example, if the assessment showed that your relative has been assessed as having the capacity to consent to and make the decision about their care and support and/or treatment they should be supported to do this, and their decision followed.

If an assessment was unsuccessful because it was decided that there were less restrictive options available, these should be introduced instead. For example, if the service where your relative lives wants to lock their bedroom door at night to stop them from walking round, an assessment may decide there are less restrictive options including:

- allowing your relative to stay up later
- having sufficient staff on hand to support them

The acid test

The Supreme Court's judgment of March 2014 in the case of 'Cheshire West' introduced an 'acid test' which has 3 statements. If the answer to all 3 statements is yes, then this confirms a deprivation of liberty:

1. An individual has been assessed as lacking the capacity to consent to the arrangements for their care and support and/or treatment
2. Is subject to continuous supervision and control and
3. Is not free to leave their care setting (where they are in a care home or hospital setting)

The Supreme Court also ruled that even if the individual is not objecting to a deprivation of liberty, a DoLS application is still required. The judgment marked a significant change.

If your relative is subject to a standard authorisation they must have a Relevant Person's representative (RPR) appointed. This should be someone chosen by your relative, e.g. you, another family member or friend. If they are assessed as not being able to make this choice, then the RPR is chosen by the best interests assessor. If there is no family carer, another family member or friend available then a Paid Relevant Person's Representative (PRPR) will be appointed.

If a standard authorisation is put in place, a copy of the authorisation must be given to your relative, their RPR, and anybody else who was consulted when deciding whether the deprivation of liberty was in your relative's best interest. The Care Quality Commission must also be informed. This should happen as soon as practicable.

The care home or hospital must explain the following information to your relative and their RPR as soon as practical after the standard authorisation is put in place, both verbally and in writing:

- What the effect of the authorisation is
- That your relative and their RPR both have the right to apply to ask the local authority to review the authorisation in the Court of Protection. This is known as a Section 21a appeal process
- That your relative and the RPR are entitled to ask for an IMCA advocate to be appointed to provide support throughout the Section 21a appeal process
- If you think your relative is being deprived of their liberty in a care home or a hospital, you are entitled to ask the care home or hospital to assess whether this is the case. If they do not respond promptly, you are entitled to ask the local authority to investigate

DoLS in supported living, family or own home

If your relative is deprived of their liberty in a supported living setting, family or own home then this must be carried out via an application to the Court of Protection to ensure it is legal, the least restrictive option and in their best interests.

If the Court of Protection authorises the DoLS then your relative is entitled to a Rule 1.2 Representative.

This role is similar to that of the Relevant Person's Representative (RPR) role and responsibilities include:

- Having regular contact with the person (your relative) deprived of their liberty
- Helping your relative to understand their DoLS authorisation and how it affects them
- Assist your relative to exercise their rights, e.g. if they want to challenge the authorisation
- Ensure any conditions attached to the authorisation are met, referring any concerns to the court if necessary
- If appropriate, ask for an early review of the authorisation
- Provide feedback at the end of an authorisation

What is a Rule 1.2 Representative?
Guide by VoiceAbility

Usually a social worker will decide whether the role of Rule 1.2 Representative is a family carer, other family member or friend (unpaid) or a professional independent advocate.

Key message:
If your relative is in a mental health service and they meet the criteria for detention under the Mental Health Act, they should not be subject to the Deprivation of Liberty Safeguards.

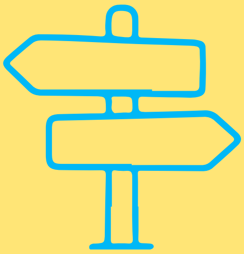
The Deprivation of Liberty Safeguards should not be used if the main reason is to restrict contact with individuals who may cause your relative harm. If it is believed to be in a relative's best interests to restrict contact with individuals an application should be made to the Court of Protection.

Read this case study from the Advonet Group about how their client was supported to make a complaint about their treatment whilst under a DOLS. It demonstrates how the professional independent advocate's only focus was ensuring their client's voice was heard and not being distracted by feedback from the service.

DoLS examples from practice

By Social Care Institute for Excellence (SCIE)

Ben, Isabel, Millie, Mr J and Jehan are all case studies about people with a learning disability, autism or both. Millie's includes how an IMCA was involved to provide support. Mr J's is about a young man who was admitted to hospital 50 miles away in an emergency. By showing that his human rights were breached, this resulted in a positive outcome. Jehan's case study describes how staff were required to complete additional training to prevent the use of restraint.



The local authority case study provides information about how a local authority was proactive in assessing people during their transition from childhood to adulthood (e.g. to acknowledge that as an adult we are all permitted to have more choice and control over our lives) to ensure that if people continued to have restrictions on their life, they were lawful, appropriate, proportionate and in their best interests

Read the case studies

Further information

DoLS IMCA by Cloverleaf Advocacy
Read this information about the role of an independent mental capacity act advocate including a factsheet to download from Cloverleaf
https://cloverleaf-advocacy.co.uk/advocacy/dols-imca

Deprivation of Liberty Safeguards by BILD, NAS and Action on Elder Abuse. This guide is for family carers
https://torbayandsouthdevon.nhs.uk/uploads/dols-a-guide-for-familyfriends-and-unpaid-carers.pdf

Template Letters by Irwin Mitchell Solicitors
Use these template letters from Irwin Mitchell Solicitors if you are concerned that your relative is being deprived of their liberty without authorisation

1. The first letter is to be sent to the manager of the hospital or care home requesting that a DoLS authorisation be put in place
2. The second letter is to be sent to the local authority in the event that no satisfactory response is received to the above letter
3. The third letter is to be sent to the relevant social worker where an individual is deprived of his or her liberty in a placement that is not a registered care home or hospital, e.g. supported living

Deprivation of liberty safeguards: a practical guide by the Law Society
The Law Society has information about DoLS including quick reference guides for different settings which can be used as a checklist to identify whether your relative is being deprived of their liberty
https://www.lawsociety.org.uk/topics/private-client/deprivation-of-liberty-safeguards-a-practical-guide

DoLS example from practice by Social Care Institute for Excellence (SCIE)
Read practical examples of how the Deprivation of Liberty Safeguards (DoLS) are applied in real life situations, including how decisions are made in a person's best interests when they may be deprived of their liberty.
Note: not all the examples are for people with Severe Learning Disabilities.
https://www.scie.org.uk/mca/dols/practice/examples/

Mental Health Act 1983

This section of the Family Carer Advocacy Pack is about the Mental Health Act 1983, when and how it is used, your relative's rights and your rights (as a family carer or Nearest Relative).

What is the Mental Health Act?

The Mental Health Act (MHA) 1983 is the law which allows your relative to be admitted, detained (sectioned) and treated if their wellbeing or safety are at risk, or to protect other people. The term "section" describes which part of the MHA has been applied (e.g. Section 2) and the set of rules which are used to keep your relative in a mental health service.

A person can only be detained under the Mental Health Act or 'sectioned', if:

- They need to be assessed or treated for a mental health condition. Assessment is covered by Section 2 of the MHA, while treatment comes under Section 3.
- They might pose a serious risk to themselves or another person if they did not receive treatment, e.g. behaviour described as challenging.
- They have a mental health condition that is serious, and their health would be at risk of getting worse if they did not get treatment.
- They have been found guilty of a criminal act and their admission has been ordered by a Court (because prison has been identified as inappropriate). This is Part III of the Act and relates to Patients Concerned in Criminal Proceedings or Under Sentence, sometimes called a 'forensic' section

Visit the Rethink Mental Illness webpage for further information including a video clip
Watch this video clip 'Making Sense of Sectioning' from Mind

All our information sheets are available to download free of charge because we believe that money should not be a barrier to getting the information you need when you need it.

Please see the end of this information sheet for details of how to support us.

We want to make sure our resources are helpful. Please spend a few minutes giving us some feedback: Feedback form

The UK Supreme Court has unanimously overruled the 2014 decision in Cheshire West in a significant judgment (UKSC 16, 2 June 2026), we are awaiting updated guidance about how to assess if someone is deprived of their liberty. Therefore some of the information in this resource is out of date and will be updated in due course.

A number of factors can increase the likelihood of admission to a mental health service, but should not be the main reasons:

- If there are no community-based assessment and treatment services available in their area
- If their community placement has broken down
- If their family can no longer provide accommodation and care and support
- If the care and support they are receiving (in the community) is failing to address their emotional and/or mental health needs and/or behaviour described as challenging
- Transition from children to adult services has been poorly managed and they are in a position where there is no community based placement available following the end of their educational placement

If your relative has previously been in a mental health service and discharged, or you are worried that there is a possibility that they will be placed in a mental health service, ask the professionals involved in their care, support, and/or treatment to support you to develop a crisis plan.

Key message: If you (family carer), other family members, friends or paid support staff notice a change in your relative's emotional and/or mental health or behaviour described as challenging you can ask for a Care and Treatment Review (CTR).

Read this guide from Bringing Us Together about the process.

If the situation is urgent and there is no time to organise a CTR a request for the Blue Light Protocol can be made.

Read this Crisis Prevention Guide from Bringing Us Together

If your relative is detained under the Mental Health Act, these 5 guiding principles should be followed:

1. Least restrictive option and maximising independence. Where it is possible to treat your relative safely and lawfully without detaining them, this is what should happen. Wherever possible your relative's independence should be encouraged and supported with a focus on promoting their recovery. They should maintain skills, develop new ones but not lose any existing skills.

2. Empowerment and involvement. Your relative should be fully involved in decisions about their care, support and/or treatment. Your views (family carer), other family members and friends, if appropriate, should be fully considered when decisions are made. If decisions are made which are not in line with the views expressed by your relative, the reasons for this should be given.

3. Respect and dignity. Your relative, you (family carer), other family members and friends should be treated with respect and dignity and listened to.

4. Purpose and effectiveness. Decisions about care, support and/or treatment should be appropriate for your relative (e.g. person centred) with clear therapeutic aims, promote recovery and should be delivered to current national and/ or current available best practice guidelines, for example Mental Health Act Code of Practice, National Institute for Health and Care Excellence (NICE).

5. Efficiency and equity. Providers, commissioners and other relevant professionals and organisations should work together to ensure that the quality of commissioning and delivery of mental health services are of high quality and considered as equally important as physical health and social care services. All relevant services should work together to ensure timely, safe, and supportive discharge to the community.

> **“Where it is possible to treat your relative safely and lawfully without detaining them, this is what should happen.”**

This is probably the most important statement from the Act. Your relative (if they have capacity) or you (on their behalf as their family carer) should always ask “What are the benefits of being admitted to a mental health service. What care, support and/or treatment is being offered that can’t take place in the community”. Admission to a mental health service should always be avoided wherever possible for the following reasons:

- Admission and detention may result in a further deterioration in emotional and/or mental health or increase in behaviour described as challenging due to:
    - separation from a person’s family or friends. Placements are typically far from home, for long periods which isolates your relative from their family, friends, and wider community
    - the hospital environment makes it difficult to deliver person-centred care, support, and/or treatment. For instance due to difficulties adjusting lighting, noise, or access to preferred activities.
- Loss of skills necessary to thrive in the community because of a lack of opportunity to practice, e.g. cooking, shopping
- Limited choice and control
- “The average weekly fee of £3,500 per patient was no guarantee of patient safety or service quality.”….. “Hospitals for adults with learning disabilities and autism should not exist but they do. While they exist, they should be regarded as high-risk services i.e. services where patients are at risk of receiving abusive and restrictive practices within indefinite timeframes. Such services require more than the standard approach to inspection and regulation. They require frequent, more thorough, unannounced inspections, more probing criminal investigations and exacting safeguarding investigations” (Source: Margaret Flynn, Winterbourne View Hospital Serious Case Review)
- Mental health institutions have been identified as at a great risk of developing ‘closed cultures’ and can have an increased risk of the use of restrictive interventions.

There are several national programmes which aim to support the discharge of people and reduce admissions because it is recognised that mental health services for people with a learning disability, autism or both are not necessarily appropriate or safe places. This includes the government's national 'Building the Right Support' programme.

In this video self-advocates and family carers talk about their experiences and views of mental health services. Watch the video here

Before your relative can be lawfully detained they will be assessed by a team of health care professionals:

- Approved Mental Health Professional (AMHP). An AMHP is a health care professional (e.g. nurse, occupational therapist, psychologist) who is specially trained to carry out certain duties under the Mental Health Act.
- a doctor who has special training in mental disorders, called a 'section 12 approved doctor'
- another doctor

At least one of the health professionals must have met your relative previously.

There are many different types of section, but the main ones are:

Section 2

This section of the Mental Health Act authorises the detention of a person for assessment of their mental health condition (or assessment followed by treatment). Detention under Section 2 can normally only last for up to 28 days.

People with a learning disability, autism or both are considered under the MHA to have a 'mental disorder' and can be detained:

- Their behaviour is associated with abnormally aggressive or seriously irresponsible conduct of a nature or degree which warrants their detention for assessment
- There is a need to detain the person in the interests of their own health or safety or with a view to the protection of others
- The symptoms they are showing (of a mental health condition) warrants their detention for assessment

Section 3

This section of the Mental Health Act authorises the detention of a person so that they can receive treatment for a mental health condition. Detention under Section 3 can last for an initial period of up to 6 months, after which it can be renewed if necessary. People with a learning disability, autism or both can be detained under section 3 of the MHA if:

- Their behaviour is associated with abnormally aggressive or seriously irresponsible conduct of a nature or degree which makes it appropriate for them to receive medical treatment and
- It is necessary for the health or safety of the person or for the protection of others that they should receive treatment and it cannot be provided unless they are detained
- Their mental health condition makes it appropriate for them to receive medical treatment

Key message:
The way in which the Mental Health Act is used for people with a learning disability, autism or both is changing. The proposed revised Act will make it harder to admit your relative to a mental health service unless there is a clear clinical mental health diagnosis. Having a learning disability, autism or both will no longer be considered a mental disorder.

For further information read:

This page from the Local Government Association
This article from learning disability today
This information on the Challenging Behaviour Foundation's website

Voluntary/informal patient

If your relative has been assessed as having the capacity to consent to treatment as a voluntary patient, this may seem like a better option than being sectioned and there are some advantages:

- Your relative should be entitled to more freedom. For example, they can leave the ward when they want although they will be expected to engage in a treatment plan which will mean spending some scheduled time in the mental health service. Mental health services are locked but if your relative is a voluntary patient, staff should provide clear instructions about what they need to do if they want to leave the service
- They can refuse treatment, including medication

But also disadvantages:

- They lose their right to the protection the MHA provides.
- Discharge planning is not as detailed and there is no entitlement to Section 117 aftercare (which has a funding stream). This means they could be discharged without the right community support
- Increased risk of readmission (if community support or aftercare are not in place)
- If your relative attempts to leave the service but the doctor or nurse involved in their care feels they meet the criteria for detention your relative could be held for a period of time (up to 72 hours) to allow for a formal mental health assessment to be completed under Section 5 Holding Powers

Admission with a Deprivation of Liberty authorisation in place

Admission to a mental health service will include restrictions. These need to be within a legal framework, for example detention under the MHA. If your relative is assessed as lacking the capacity to consent to admission to a mental health service and they object e.g. by trying to leave the service, they can be detained under the MHA.

Even if your relative does not object, they are still being deprived of their liberty by simply being in the service and without a DoLS this is unlawful. If you think this applies to your relative, raise this issue with their commissioner, responsible clinician, or professional independent advocate and/or speak to a solicitor. If your relative is deprived of their liberty the full guidance should be followed, e.g. best interests decision, the least restrictive option.

There are different types of mental health services available for people with a learning disability, autism or both. The type of service your relative is admitted to should depend on their individual need. The provider of the service may be the NHS or an independent provider.

Read this report from CQC "Monitor the use of the Mental Capacity Act Deprivation of Liberty Safeguards 2012/13". Appendix A (pg 53-54) includes a case study about a resident of Winterbourne View:

Click here to read the report

Read about other types of sections here

Key Message:
Make sure you and your relative are clear about their legal status

Advocacy and the Mental Health Act

Self-advocate

If your relative is assessed as having capacity, they can advocate for themselves. They can do this with support from you (family carer) and/or an Independent Mental Health Act Advocate.

Independent Mental Health Advocate (IMHA)

Your relative has a statutory (legal) right to an Independent Mental Health Advocate, if they are:

- Detained under the MHA
- A conditionally discharged restricted patient
- Subject to Guardianship under the MHA
- Receiving supervised Community Treatment

An IMHA advocate can support your relative by helping them understand:

- The reasons for their detention and how to appeal using the Mental Health Review Tribunal process
- Their rights under the Mental Health Act and the safeguards that apply
- Any conditions or restrictions which apply
- The treatment they are currently receiving or might be given and any requirements that would apply in connection with the treatment

An IMHA can also support your relative to:

- Access information e.g. by ensuring it is provided in a format that your relative can understand. This could be easy read or organising a BSL interpreter
- Talk with staff and prepare for meetings to ensure their voice is heard
- Explore their options and be involved in decisions about their care and support and/or treatment
- Raise queries or concerns about the treatment they are receiving

To support them in their role IMHAs have the right to:

- Access the mental health service your relative is using
- See your relative in private unless they are under close observation, in seclusion, long term segregation or clinical staff advise against it for safety reasons. If your relative is moved to seclusion the mental health service should inform their IMHA and if your relative agrees offer the IMHA the opportunity to be involved in reviews
- Attend meetings with staff if your relative requests this
- Meet with and hold discussions with professionals involved in your relative's care and support and/or treatment
- Access relevant records if your relative provides consent. If your relative has been assessed as not having the capacity to consent, then access to the records should be permitted if it contributes to the IMHA carrying out their role effectively

Watch this video from SCIE about improving the quality of access

This case study from Cloverleaf Advocacy shows the positive impact having an IMHA had for somebody they represented

Family Carer Advocavcy

Unless there is a clear reason, the Mental Health Act states that family carers should be involved in the care, support and/or treatment of their relative.

Nearest Relative

Additionally, there is a legal entitlement for a family member to act as the Nearest Relative. Nearest Relative is a legal term used in the Mental Health Act 1983. It gives one member of your relative's family certain rights and responsibilities if they are:

- Detained under sections 2, 3, 4 or 37
- Under a community treatment order (CTO)
- Under a guardianship order

Nearest Relative is not the same as next of kin. A next of kin has no rights under the Mental Health Act.

Who can be the Nearest Relative Section 26 of the Mental Health Act 1983 sets out who can be the Nearest Relative. The list is in strict order and the person who is highest on the list is the Nearest Relative.

1. Husband, wife, or civil partner (including cohabitee for more than 6 months)
2. Son or daughter
3. Father or mother (an unmarried father must have parental responsibility in order to be nearest relative)
4. Brother or sister
5. Grandparent
6. Grandchild
7. Uncle or aunt
8. Nephew or niece

In certain situations a Nearest Relative can be displaced (changed). These include:

- They cannot act because of health reasons
- They have unreasonably objected to a section 3 or guardianship application
- They have tried to discharge the person they are representing without considering all the circumstances, e.g. will the person be safe, where will they live, who will provide the necessary care and support and/or treatment
- They are unsuitable to act
- There is no Nearest Relative from the list
- It is not practical to identify the Nearest Relative

The role and rights of the Nearest Relative

The role of the Nearest Relative is an important safeguard for people who are detained under the Mental Health Act. It is another way of making sure that your relative's rights are protected when they are unwell and there is somebody they trust involved in their care, support and/or treatment. If you are identified as the Nearest Relative then the following applies:

- The Approved Mental Health Professional (AMHP) must let you know within a reasonable time if your relative is to be detained under Section 2 of the MHA. They should provide the following details:
    - their name and contact details
    - the names of the 2 doctors (involved in the assessment and decision to detain your relative)
    - the date of the assessment and the outcome
- The AMHP must speak to you before your relative can be detained under Section 3 of the Mental Health Act, unless it is not reasonably practical/would cause unreasonable delay. If you object, then the detention under Section 3 cannot go ahead unless the Court removes you as the Nearest Relative. This is known as displacement of the Nearest Relative.
- You can request Adult Social Care consider carrying out an MHA assessment to decide if your relative should be detained or placed under a guardianship order.

- You can object to your relative being detained or placed under a guardianship order
- You can discharge your relative if they are detained. The Responsible Clinician (RC) can stop the discharge in certain circumstances. In this instance you can apply to a Mental Health Tribunal
- You can ask for involvement from an Independent Mental Health Act (IMHA) advocate
- You must be consulted and/or given information. If your relative has been assessed as having the capacity to decide the level of involvement, they want from others this will be followed
- You can appoint someone else to act as the Nearest Relative

For further information read this factsheet from Mind

Read this series of three guides produced by the Equality and Human Rights Commission about the Mental Health Act. Each section contains the option to record whether you and your relative think good practice is being followed.

Equality and Human Rights Commission

The first guide is about your relative's rights if they are detained under Section 2 or 3 of the MHA or in a mental health service as a voluntary patient:

Click here to read the guide

The second guide is about your relative's rights if they are detained because they are suspected or have been convicted (found guilty) of a crime:

Click here to read the guide

The third guide is about:

- Who can support your relative and their role and responsibility
  - nearest relative
  - responsible clinician
  - independent Mental Health Act Advocate
  - care co-ordinator
  - hospital manager
- About length of stay in a mental health service
- Treatment
- Type of service and ward
- Information about personal belongings (in the mental health service)
- Your relative's right to continue to do the activities they enjoyed
- Reasonable adjustments
- Cultural needs
- What happens to your relative's home and belongings, their job/volunteer roles, benefits and bills

Click here to read the guide

Further information

If you are unhappy with your relative's detention Irwin Mitchell provide free legal surgeries:
Information about Assessment & Treatment Unit solicitors
https://www.irwinmitchell.com/personal/protecting-your-rights/assessment-and-treatment-unit-solicitors

Blog about reducing mental health detention of people with a learning disability, autism or both: https://insights.doughtystreet.co.uk/post/102hfgz/reducing-mental-health-detention-of-people-with-autism-and-or-learning-disabiliti

Read this Challenging Behaviour Foundation guide: My family member has been sent to an inpatient unit - What do I need to know?
https://www.challengingbehaviour.org.uk/wp-content/uploads/2021/02/4-My-family-member-has-been-sent-to-an-inpatient-unit-what-do-I-need-to-know.pdf

Full set of 'Meeting the Challenge' guides:
http://www.challengingbehaviour.org.uk/information-and-guidance/when-things-go-wrong/assessment-and-treatment-units-atus/

The Care Quality Commission (CQC) are responsible for regulating, inspecting (against 5 key questions: is the service safe, effective, caring, responsive to people's needs, and well-led) and rating both NHS and independent mental health services.

In addition, they are responsible for checking that mental health services are following the law (Mental Health Act) for anyone who is detained or under a Community Treatment Order. They do this by carrying out visits and meeting with people (in private) and listening to their experiences.

If during inspections or visits the CQC are concerned about the use of medication, e.g. somebody appears heavily sedated (sleepy) they can appoint a Second Opinion Appointed Doctor to explore this further and check that the medication people are receiving is correct.

If you have any concerns about what you see or hear (even if it is not related to your relative's care and support and/or treatment) then you can contact the CQC directly:

Contact the CQC: https://www.cqc.org.uk/contact-us

Information about how to raise a complaint with the CQC about the use of the Mental Health Act: https://www.cqc.org.uk/contact-us/how-complain/complain-about-service-or-provider

Guardianship Order

If detention (section) under the Mental Health Act is suggested for your relative, ask whether a guardianship order is an option. This will allow your relative to receive treatment under the Mental Health Act (Section 7) in the community instead of a mental health service. If approved, a guardianship order is a better option then being detained (sectioned) because it means your relative will have less restrictions placed on them and be able to go about their daily life with more freedom.

Your relative can only be placed under a guardianship order if it is absolutely necessary for their wellbeing or to safeguard other people and must be approved by two doctors

Who can be your relative's guardian

The appointed guardian may be the local social services authority, or someone who has been approved by a social services authority. If the guardian is not a social services authority, they are called a 'private guardian'.

A Guardian has the legal power to tell your relative:

The three As:

Abode	Where they live
Attendance	To attend appointments for medical treatment, work, education or training at set places and at set times
Access	To allow a doctor or another named person to see your relative

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Please see the end of this information sheet for details of how to support us.

We want to make sure our resources are helpful. Please spend a few minutes giving us some feedback: [Feedback form]

How to apply for a guardianship order

- An application is made via an approved mental health professional (AMHP) or the Court is made
- As part of the application process, there is a case conference involving your relative, you (as family carer and/or nearest relative) and all relevant professionals
- The conference will cover how your relative's needs are going to be met and whether a guardianship order is the right decision
- If the application for a guardianship order is agreed by the local authority it will last 6 months. It can then be renewed for another 6 months
- After this, the guardianship order is renewed once a year
- The renewal must happen within the last two months of the guardianship order period

Ending the guardianship order

- Every time the guardianship order is renewed, you (if you qualify as the nearest relative) or mental health professionals can decide whether or not it should be ended. This decision needs to be approved by the local authority
- Each time the guardianship order is extended your relative can appeal to a Mental Health Tribunal to end it
- Sometimes the local authority decides the nearest relative (this could be you) cannot discharge your relative. If this happens you can ask a Mental Health Tribunal if they will discharge your relative
- The local authority or your relative's responsible clinician can discharge your relative from a guardianship order at any time
- A guardianship order ends immediately if your relative is detained (sectioned)

Your relative has a statutory entitlement to an Independent Mental Health Act advocate if they are placed under a guardianship order.

Click here to visit the Mind website

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Criminal Justice System

This section of the Family Carer Advocacy Pack is about what to do if your relative becomes involved in the Criminal Justice System (CJS):

- As a suspect
- As a witness
- If a decision is made about a place of safety
- As a victim

and how you can support them as a family carer.

As a suspect

People with a learning disability, autism or both are over-represented in the criminal justice system (CJS).

- Autistic people are 7 times more likely to come into contact with the police than the general population, and 15% of young people in custody are autistic
- Young people with learning disabilities are 10 times more likely to find themselves in custody than their peers without a learning disability, and represent about 30% of people in custody
- It is thought that about 10% of the prison population has a diagnosed learning disability, but around 60% of prisoners (as well as those in custody) have difficulties with communication

Source: Association for Real Change (ARC) 'People with learning disabilities in the CJS: A guide for carers and learning disability services', England 2016

People with a learning disability, autism or both become involved in the CJS for a number of reasons, including:

- Lack of early intervention and skill teaching, e.g. sexual appropriate behaviour
- No formal or a delay in receiving a diagnosis which results in inadequate support, e.g. not meeting the threshold for social services input

Read the Sexual Behaviour factsheet from the CBF

- Unusual or behaviour described as challenging, which can be misinterpreted by the public and police
- Social naivety. This can mean that people are easily taken advantage of e.g. mate (hate) crime. This term refers to people with a learning disability, autism or both being befriended by people who then exploit (take advantage of) them

Watch this video clip called Tricky Friends with your relative to help explain what friends should do (and not do)

- Communication difficulties, e.g. not understanding what is being said, what is required of them and how this is interpreted by professionals such as the police
- Suggestibility and acquiescence. This means 'going along with what somebody has said' whether because of a lack of understanding or because your relative thinks that agreeing is the right thing to do. This may lead to a false confession
- More likely to get caught and less likely able to conceal a crime
- Substance misuse
- They do not want to acknowledge or are embarrassed to disclose their learning disability, autism or both

Sometimes people with a learning disability, autism or both become involved in the CJS because support staff (community and hospital services):

- Call the police when they are unable to manage behaviour described as challenging
- Want to take action against the person with a learning disability, autism or both due to the behaviour described as challenging. Instead of recognising this as communicating an unmet need or a sign of distress they view it as an 'assault'

Read the full ARC report here including the policing pathway - from allegation through to prosecution

To reduce the risk of this happening, family carers can:

- Ask services what their policy is at an organisational level. They cannot prevent a member of staff taking action at a personal level
- Liaise with the local police and ask their advice about the potential of this happening
- Make sure that your relative's care and support and/or treatment and positive behaviour support plans contain detailed information about what to do to prevent behaviour described as challenging, early warning signs, triggers for behaviour, types of behaviour, what to do and what might make a behaviour escalate. For example, if your relative's support plan states that all types of touch (including physical restraint) cause an extreme response because of tactile defensiveness (find touch uncomfortable) and should therefore be avoided. If support staff do not follow this guidance, this places accountability with them not your relative

Until a court, following a police investigation, decides a crime has been committed, the offence is only alleged and your relative has the same legal rights to a defence.

If your relative is found guilty of an offence but it is recognised by the CJS that they would be unable to cope with a prison environment, they should be assessed and diverted to another more appropriate service, which may be a mental health service. The identified service should be able to address their care, support and also their offending behaviour needs, e.g. education about appropriate sexual behaviour, recommendations about better community support.

Read Stan's story:
Stan had been told that he might be sentenced to prison. He was therefore relieved when he realised this was not the case. Stan was given a community sentence that involved a curfew between the hours of 6pm and 7am.

Within a week Stan was returned to court for breaking his curfew – he had been playing football with his friends in the local park at 7pm. Stan didn't know what the word 'curfew' meant, and he didn't have a watch because he couldn't tell the time.

Stan was sentenced to prison, where his learning disability was recognised. He was later diverted away from prison into a secure mental health unit. Stan subsequently received support to help him to live independently in the community. He now does voluntary work, which involves giving talks to school children about why it is important to stay away from crime. (Source: Prison Reform Trust)

Further information about Liaison and Diversion services

This document produced by the Crown Prosecution Service explains the process of being a witness (either as a victim or an observer of a crime) and the support your relative is entitled too, e.g. referral to victim support. There are case studies you can read including one about involvement from a professional independent advocate

If a decision is made about a place of safety

Your relative may become involved with the CJS because it has been identified that they need to be 'removed to a place of safety' for their own protection or the protection of others. A place of safety could be a mental health service or police station. Taking someone to a place of safety is to allow them to be assessed by a doctor and interviewed by an approved social worker. The maximum time someone can be detained is 48 hours. If the police remove someone under the Mental Health Act to a police station, the person being removed is entitled to:

- Have another person of their choice informed of their whereabouts (this could be a family carer)
- Access to legal advice
- The support of an 'Appropriate Adult' (this could be a family carer)
- Medical treatment from a suitable healthcare professional if needed, e.g. if they have a physical injury

As a Victim

Being a victim of a crime is a distressing situation, and for your relative this might involve:

- Being interviewed
- An impact on self-esteem and confidence, e.g. did this happen to me because I have a learning disability, autism or both
- Conflict of loyalty, e.g. mate crime - "I thought they were my friend. I didn't know what they were doing to me was wrong"
- Providing evidence if the case goes to court

Your relative's rights

If your relative is identified as a vulnerable person under the Police and Criminal Evidence Act 1984 Code of Practice they will be entitled to support from an Appropriate Adult. The police should not interview your relative until the Appropriate Adult is present. The exception to this is if a delay would result in a risk of harm to property or people. An Appropriate Adult should not be employed by the police and have experience of supporting people with a learning disability, autism or both. You, another family member or friend can act as your relative's Appropriate Adult but if you do not feel able to take on this role then it is the responsibility of the police to identify somebody on your relative's behalf.

An Appropriate Adult can request reasonable adjustments (Equality Act 2010), e.g.

- Sensory needs: where your relative is interviewed
- Communication needs: the way in which information is presented, somebody who can sign
- Access to disabled toilet, food and drink, regular breaks

This link provides information from gov.uk about your relative's rights as a victim of a crime

Watch this video on being an Appropriate Adult

Visit this webpage for more information about liaison and diversion if your relative becomes involved with the Criminal Justice System as a suspect. It includes case studies and video clips.

Taking proactive action

Read this fact sheet (including a template form to share useful information about your relative with the police) about asking if your relative can be 'flagged' on the police system. This is like a 'reasonable adjustments' flag for health care services. Not all police systems operate a flag system but there are other ways they can record information that alerts them to your relative's needs.

The type of information which is useful to share includes:

- Information about who to contact in an emergency
- The address of your relative. This means that if the police have to visit your relative's home, they will be aware that somebody vulnerable lives there, what their needs are and the best way to interact with your relative
- Communication needs, e.g. my relative uses sign language to communicate, my relative may repeat what you say (echolalia), they are not being disrespectful
- Sensory needs, e.g. my relative is tactile defensive (reacts strongly to being touched). Please consider ways for them to co-operate with you without touching them. Instead of guiding them physically, tell them what you want them to do, or show them

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Litigation Friend

Having a 'Litigation Friend' allows your relative to access the justice system fairly and with support, for example a court case relating to:

- A civil case (e.g. if your relative wants to take legal action against a provider because of abuse)
- A Court of Protection case

Who can be appointed a Litigation Friend

There are two groups of people who can be appointed as a Litigation Friend:

1. A person with authority as a Deputy
2. If there is no appointed Deputy, then an Appropriate Adult (this could be you) can put themselves forward as a Litigation Friend. You will need to meet certain criteria:
   - You can fairly and competently conduct proceedings on behalf of the protected party (your relative)
   - You have no interest adverse to that of the protected party (your relative) and
   - You undertake to pay any costs which the protected party (your relative) may be ordered to pay in relation to the proceedings subject to any repayment they might be entitled to

This link provides further information from gov.uk about Litigation Friends

Read this information from the CBF about Legal Support

Case Studies

John

John has an autistic spectrum disorder and mild learning disabilities. He was a victim of mate crime (when a person is harmed or taken advantage of by someone they thought was their friend) and was arrested because his flat was used by 'friends' to store marijuana plants. The arresting officer noticed that John was not responsive to his questions and did not give eye contact. John kept talking about needing to go home to watch EastEnders at 7pm. The officer called for an Appropriate Adult because he felt that John had a communication difficulty and needed help to understand what was happening. The Appropriate Adult spent time with John explaining what was happening. She gave him time to understand what she had said after each sentence and also wrote down the questions so he could read them. At times she used pictures. She drew his house and where his friends lived and asked him to name his friends who stored the plants in his house. She asked him if he preferred her not to look him in the eye and he said yes. The information gathering took longer, but by using these reasonable adjustments they were able to get a clearer picture of what was going on.

Pete

A community psychiatric nurse supported a client with mild learning disabilities with an intervention to reduce his drug taking. He realised that simply talking about the pros and cons of taking drugs was not helping Pete, so he printed out a photo of a set of weighing scales from the internet and stuck it to a flip chart which was divided into two columns with 'good things and 'bad things' about taking drugs. He talked to Pete and wrote down Pete's responses in simple language accompanied with images, such as a pound sign to represent having more money, and a set of bars to represent going to prison. After the session he gave it to Pete to go home and look at it for homework. The visual representation really helped Pete and he began to respond to treatment.

Matt

Matt was arrested for assault. While in police custody he was seen by a nurse who thought he might be on the autistic spectrum. Although Matt didn't have a formal diagnosis of autism, his family reported concerns about his behaviour consistent with that reported by the nurse. Matt's case went to court, and he was found guilty of assault. During his trial, the magistrates felt that something wasn't "quite right" and asked for a medical report to help them decide what sentence would be appropriate. Matt was remanded into custody for medical reports, which took longer than expected. Eventually Matt was seen by two doctors and their reports were presented to the court. Both reports described Matt as being on the autistic spectrum with underlying psychosis and recommended hospital to see if Matt would respond to treatment. He is currently in a low secure hospital ward in his local area that specialises in autistic spectrum disorders and mental illness. Matt now has a diagnosis, which means he is likely to receive appropriate treatment and support for his condition. This, in turn, should help him to manage his behaviour and reduce re-offending.

(Source: Rethink Mental Illness)

Further information

This report was commissioned by the LGA for the Greater Manchester Health and Justice Steering Group (Learning Disability and Autism). It details how the Criminal Justice System, and its prevention partners are working to address the challenges faced by people with a learning disability, autism or both people. It includes a section about family carers, how they have supported their relative and what support for them should look like: https://www.local.gov.uk/publications/people-learning-disability-and-autism-criminal-justice-system

NHS Health Education England: Working in community settings with people with learning disabilities and autistic people who are at risk of coming into contact with the CJS. A resource for health and social care staff:

http://www.researchgate.net/publication/354089773_Working_in_community_settings_with_people_with_learning_disabilities_and_autistic_people_who_are_at_risk_of_coming_into_contact_with_the_criminal_justice_system_A_resource_for_health_and_social_care_s

Resources provided by Keyring https://www.keyring.org/cjs/useful-resources

Information and guidance from the National Autistic Society https://www.autism.org.uk/advice-and-guidance/topics/criminal-justice/criminal-justice/professionals

Books Beyond Words has a range of picture stories about involvement in the CJS https://www.booksbeyondwords.co.uk/bookshop/criminal-justice

NHS guidance about ensuring the healthcare needs of people with a learning disability, autism or both are met whilst in prison http://www.england.nhs.uk/wp-content/uploads/2021/09/B0707-meeting-the-healthcare-needs-of-adults-with-a-learning-disability-and-autistic-adults-in-prison.pdf

The charity User Voice has published this report titled "Neuro…What? Neurodiversity in the Criminal Justice System" including personal accounts http://www.uservoice.org/consultations/neurodiversity/

Report from Keyring (including case studies demonstrating positive outcomes and identifying areas which need to improve) https://www.keyring.org/uploaded_files/1791/images/Fairer%20Justice%20Report.pdf

This guidance is for the criminal justice system and how they can support autistic people
http://www.gain-grantham.co.uk/wp-content/uploads/2016/12/ASD-and-Criminal-Justice.pdf

Police factsheet from the Challenging Behaviour Foundation
https://www.challengingbehaviour.org.uk/wp-content/uploads/2021/02/CV019-Police-Factsheet.pdf

Children and Families Act 2014

This section of the Family Carer Advocacy Pack covers the Children and Families Act 2014 which is relevant if your relative is 25 years old or under. Early intervention and good planning for the transition from child to adulthood is a key element of this Act. If your relative's rights from this Act and the Care Act are followed, then they should experience a seamless transition from children to adult services. This period is recognised as a trigger point for crisis, which often results in admission to a mental health service so it is important to know what should happen.

As with the Care Act 2014 the Children and Families Act has brought together a number of different laws and added some additional rights. The Act's main aim is to protect children who are considered vulnerable or at risk and raise the profile of children with special educational needs and disabilities. This group of children are likely to interact with local government agencies more often and the Act sets out their entitlements (and their families).

There are 10 parts to the Act:

- **Part 1:** Adoption and Contract
- **Part 2:** Family Justice
- **Part 3:** Children and Young People in England with Special Educational Needs and Disabilities (SEND)
- **Part 4:** Childcare Act
- **Part 5:** Welfare of Children
- **Part 6:** The Children's Commissioner
- **Part 7:** Statutory Rights to Leave and Pay
- **Part 8:** Time off Work
- **Part 9:** Right to Request Flexible Working
- **Part 10:** General Provisions

All our information sheets are available to download free of charge because we believe that money should not be a barrier to getting the information you need when you need it.

Please see the end of this information sheet for details of how to support us.

We want to make sure our resources are helpful. Please spend a few minutes giving us some feedback: Feedback form

Part 3: Children and Young People in England with Special Educational Needs and Disabilities (SEND)

The SEND Code of Practice sets out guidance for organisations which work with and support children and young people who have special educational needs or disabilities. Here is a summary of your relative and your (family carer) rights:

- There are clear definitions of:
    - special educational needs
    - special educational provision
    - disability
    - healthcare provision
    - social care provision
    - child
    - young person
- Children, young people and their family carers are entitled to choice and control in any decisions made
- All information should be provided in an accessible format suitable for both children, young people and their family carers to support their involvement
- Education, health and social care agencies must work in partnership, including:
    - being proactive in identifying and monitoring children and young people with SEND
    - carrying out coordinated assessments of needs
    - plan how to meet assessed needs
    - joint commissioning of support and services to meet any assessed needs
- All children and young people with SEND must have an Education, Health, and Care (EHC) plan in place, supplied by the local authority
- The local authority must consider whether to carry out an assessment for an EHC plan if a family carer, child or young person asks for it, or if a child or young person with SEND is brought to the attention of the authority
- EHC plans must be:
    - completed within 20 weeks
    - person-centred
    - outcome focused, e.g. support that enables children and young people with SEND to succeed in their education and make a successful transition to adulthood
    - reviewed regularly
    - include relevant health and social care needs
- Children and young people with SEND have the right to special education provision. The local authority is responsible for arranging this
- To support a person-centred approach the Act introduced the entitlement to personal budgets. This means that children and young people with an EHC plan and/or their family carers have more control over how allocated funding is spent:
    - Notional Budgets: Your relative and their family carers can say how they would like the funding spent but ask services to continue to manage this on their behalf
    - Direct Payments: The funding is paid directly into a specified bank account and managed independently
    - Third Party: Somebody else is nominated to manage the funding
    - or a combination of the above
- The funding may come from the local authority and/or from health

- Children and young people with SEND who are detained under the MHA have the right to special education provision. This is the responsibility of their 'home' local authority. Special provisions also need to be made, if required, when they are discharged
- Family carers have a right to mediation if they don't agree with a plan and must be kept informed of any changes
- All schools must have a qualified SEND coordinator and publish reports regularly
- Local authorities are required to publish a 'local offer' via a website which includes information about services for children and young people with SEND and their family carers. This website must include a way for family carers to give feedback and influence local service developments
- Co-ordinated early planning for transition to adult services must take place, including:
    - Care Act assessment
    - health services
    - further education, e.g. college or work
    - family carers of SEND children and young people are entitled to an assessment of their own needs to identify and provide any relevant support required and this should be recorded in the EHC plan

Rights applicable to all family carers are detailed in:

- **Part 7:** Statutory Rights to Leave and Pay
- **Part 8:** Time off Work
- **Part 9:** Right to Request Flexible Working

Advocacy and the Children and Families Act 2014

Self-Advocate

Local authorities should involve children (and their family carers) in education, care and support decisions. This includes providing additional resources, if required, to support their involvement (children and their family carers).

Family Carer Advocate

You have a right to make decisions with and on behalf of your child until they reach the age of 16 years old. The Mental Capacity Act then comes into force. Your relative can ask for you to continue to be involved or if your relative is assessed as lacking capacity you can act as their advocate. This should not prevent your relative from being involved as much as possible in making decisions and additional resources should be available to support this.

Professional Independent Advocate

If your relative will struggle to be involved in making decisions and they have nobody available to support them, e.g. family carer, other family members, friend then the local authority must fund a professional independent advocate.

Further information

Factsheet from Irwin Mitchell Solicitors explaining in detail your relative's and your (family carer) rights:
http://senadgroup.com/wp-content/uploads/2014/01/IM-Children-and-Families-Act-2014.pdf

Factsheet from Living Autism about the links between the Children and Families Act and the Care Act. The factsheet also has some case studies and links to additional resources:
https://livingautism.com/pfa-factsheet-links-children-families-act-2014-care-act-2014-autism-spectrum/

Disability Rights UK webpage providing links to resources about the Children and Families Act:
https://www.disabilityrightsuk.org/links-key-documents-children-and-families-act-2014

'Young Person's Guide to the Children and Families Act' guide published by the Department of Health:
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/359681/Young_Person_s_Guide_to_the_Children_and_Families_Act.pdf

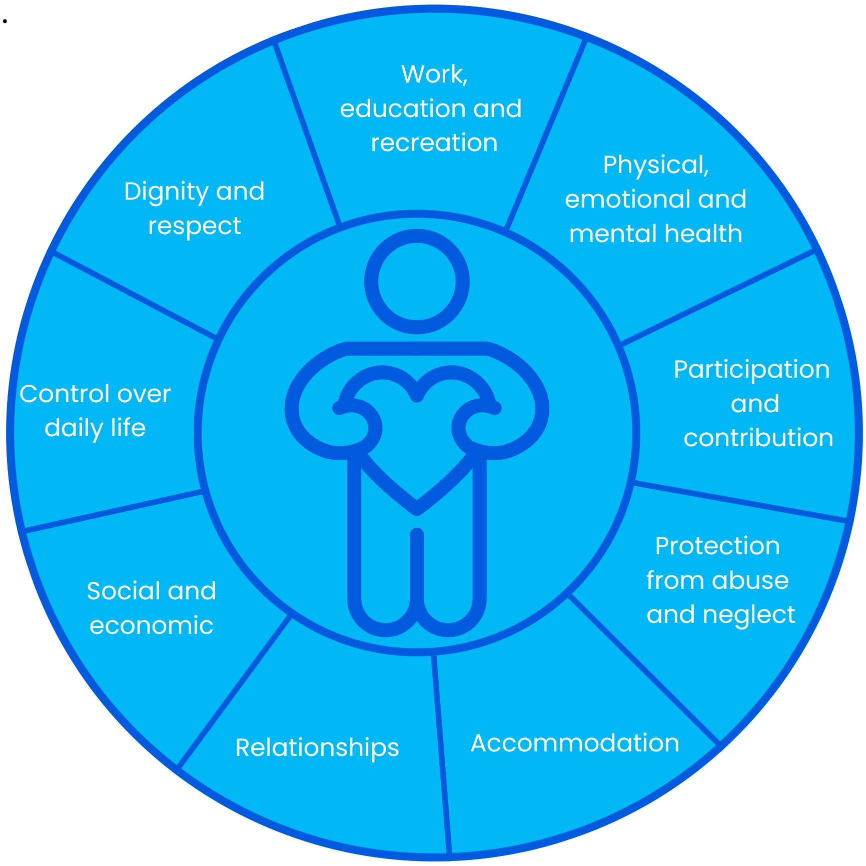
Summary of the Children and Families Act 2014:
http://www.bromleyparentvoice.org.uk/wp-content/uploads/2017/01/children-and-families-act-2014-summary.pdf

The Care Act 2014

This section of the Family Carer Advocacy Pack is about The Care Act 2014 and your relative's rights to a care and support package in the community which provides them with a good and meaningful quality of life. This is one way of protecting your relative from admission to a mental health service. There is also information about your rights as a family carer to a care and support package to ensure that you can continue in your role for as long as you want to.

What is The Care Act?

The Care Act represents the most significant change in the way care and support is provided in more than 60 years. It combines various existing pieces of law which previously decided how social care was arranged in Britain. The Act introduces the importance of 'meeting needs' instead of just 'providing services'. The Act aims to make everyone think creatively about the way a person's needs are met, rather than offering a service that may be neither what is best nor what the person needs.



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We want to make sure our resources are helpful. Please spend a few minutes giving us some feedback: [Feedback form]

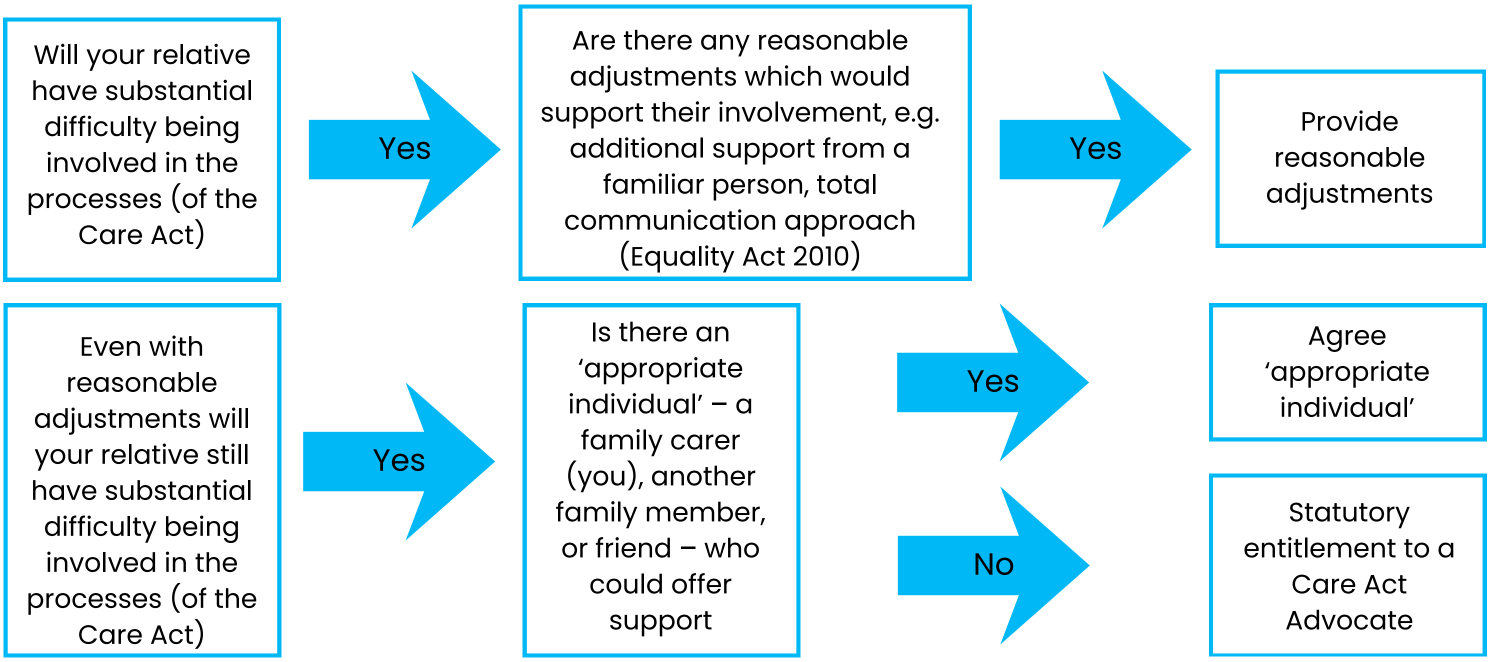
Ten key things about The Care Act?

1. Local authorities must always put your relative’s wellbeing first when making decisions about the care and support they need.
2. The views, wishes, feelings, values and beliefs of your relative should always be considered, and all decisions should be made with their involvement. Care Act guidance says, *“People should be active partners”* and *“regardless of how complex a person’s needs are, they must be supported to express their wishes and feelings, to weigh-up options and retain information to make their own decisions.”*

Watch this video introduction to The Care Act from SCIE

Watch this video about The Care Act from Rethink Mental illness

Supporting your relative’s involvement:



3. Local authorities have a duty to provide information and advice, for example about the process, what types of care and support are available. Information should be provided in an accessible way e.g. not just on a website, or leaflet in a GP’s office, but in a way that is person-centred.
4. There is a focus on early intervention to avoid crisis situations including a commitment to investing in preventative services and making full use of any existing community resources.
5. The Care Act sets out a national eligibility criteria with a minimum threshold which must be met. If your relative meets this threshold, they will have eligible needs that the local authority must then meet. Local authorities also have the option of meeting needs that fall below the national minimum threshold.
6. Your relative may have the right to a professional independent advocate if they have difficulties participating in any of the processes.
7. There are new rules to make it easier if your relative moves to a different local authority area to ensure their care and support does not change

8. If your relative is entitled to social care and support, they have the right to request a personal budget.
9. A duty to always work to protect your relative from abuse and neglect (safeguarding).
10. The Act requires the local authority to promote integration, cooperation and partnership with the NHS and other key partners.

    If your relative will experience substantial difficulty being involved in any of the processes, the local authority must identify an appropriate individual to support them. An appropriate individual is defined as 'someone who is able to prioritise the opinions of the person with a learning disability, autism or both and actively involve them in Care Act processes'.

    If there is no appropriate individual available, then the Care Act places a statutory (legal) duty on local authorities to provide a Care Act Advocate.

To be eligible for a Care Act Advocate a person must meet three criteria:

1. The person must be going through one of the processes described in the Care Act (2014), which includes (but is not limited to):
    - A needs Assessment
    - The preparation or review of a care and support plan
    - A safeguarding enquiry
2. The person must have substantial difficulty in being fully involved in these processes described in the Care Act (2014), which includes (but is not limited to):
    - Understanding relevant information
    - Retaining information
    - Using or weighing that information as part of engaging
    - Communicating their views, wishes and feelings

This visual provides a summary of the Care Act

People can experience substantial difficulty without having a cognitive impairment.

3. The person must have nobody else willing or deemed appropriate to support or represent them through the processes.

    There are exceptions to this:

    - Where the assessment or planning might result in a placement in NHS provision
        - either in a hospital for more than 4 weeks or
        - in a care home for more than 8 weeks or more
    - The local authority believes that arranging a Care Act Advocate would be in the best interests of the person
    - Where the local authority and the family carer/ other family member/friend disagree on something relating to the person, but agree that a Care Act advocate would be beneficial

Four Stages of the care assessment

1. Assessment

An Assessment is how a local authority decides whether a person needs care and support to help them live their day-to-day life. The assessment must be carried out by an appropriately trained assessor, e.g. a social worker who will consider factors such as:

- The person's needs and how they impact on their wellbeing - for instance, a need for help with getting dressed
- The outcomes that matter to the person - for example, whether they are lonely and want to make new friends
- The person's other circumstances - for example, whether they live alone or whether someone supports them
- The care and support currently being provided by a family carer

The aim is to get a full picture of the person and what needs and goals they may have. Assessments must be person-centred and you can use these tools from Helen Sanderson to capture what is important for your relative's wellbeing

2. Eligible needs

After carrying out the assessment, the local authority will then consider whether any of the needs identified are eligible for support.

3. Meeting the needs

After determining the needs which count, the local authority must decide how they will be met. Details of the support to be provided by the authority will be set out in a care and support plan.

Read the Challenging Behaviour Foundation's Ten Top Tips factsheet for getting the best support package:

4. Providing services and support

The local authority will carry out a financial assessment of any individuals with eligible needs, to determine if a contribution needs to be paid. They must provide you with a copy of their charging policy. Care Act guidance states that the local authority must leave people with enough money 'to pay for necessary disability-related expenditure (DRE) to meet needs which are not being met by the local authority'. Providing evidence is essential, e.g. bills (showing higher than average gas/ electrical usage due to extra washing, bathing due to incontinence, heating), receipts or screenshots from an Amazon account, to prove your case for these extra costs being incurred.

Support from professionals reinforces your evidence, a letter from a speech and language therapist confirming the need to purchase equipment related to meeting your relative's communication needs, e.g. printer, ink to make picture books, a letter from a psychologist confirming that when your relative is distressed they may cause breakages.

Use this template letter to request a Disability Related Assessment

The Scrap Care Charges is a group of Deaf and disabled people's organisations, parents, carers and allies working together to end social care charging and transform social care: Visit their website for more information

Read this quick guide about what to expect during assessment and care planning

Visit this SCIE link for more detailed information about assessment and eligibility

The local authority has an ongoing duty to review your relative's care and support to ensure that your relative's needs continue to be met, including carrying out a new assessment if appropriate. Read this factsheet from Mencap about review/new assessment processes which includes some case studies: Click here to access the factsheet

Transition and the Care Act

The Care Act places a statutory (legal) responsibility on the local authority to ensure a successful transition from children to adult services for your relative. There should be no gap in services during the transition period. The local authority must continue to provide any children services until adult services are in place or it is established, through the assessment process, that your relative's needs have changed, and some services are no longer applicable.

Advocacy and the Care Act

Self-Advocate

One of the key principles of the Care Act is being involved in the processes. If your relative has been assessed as having the capacity to do so they can self-advocate (represent themselves). They can of course ask for support and advice from you (family carer), other family member, friend or other important people in their life who know them well.

Click here to read a summary of the Care Act in Easy Read

Family Carer Advocate

If your relative has been assessed as having the capacity to self-advocate (represent themselves) they can still ask for your involvement in the processes. If your relative has been assessed as lacking the capacity to self-advocate (represent) themselves, they must still be supported to be involved in as much of the processes as possible, e.g. using talking mats to indicate the activities they like/dislike. You can take on the role of supporting and representing your relative, but this should not be assumed. It should be discussed and agreed with the family carer and their relative. If you agree to represent and support your relative's involvement you will only be considered appropriate if:

- You are not being paid to provide care and support for your relative
- You are not involved in any enquiry relating to abuse or neglect (safeguarding)
- Your relative has capacity (understands) and can consent (give permission) to being represented and supported by you or

- Lacks capacity (understanding) or is unable to consent (give permission) but
- the local authority is satisfied that being represented and supported by you would be in your relative's best interests
- You can demonstrate that you have regular contact with your relative
- You can show that you are able to act independently from the local authority, e.g. not employed by or involved with the local authority in any way
- There is no conflict of interest or dispute between you and your relative

Care Act Advocacy

A Care Act Advocate is trained and skilled in the processes associated with the Care Act, e.g. assessment, safeguarding and is independent of the local authority. They will ensure they have a full picture of your relative e.g. by meeting with them, accessing records and talking to those who know your relative well, taking into consideration capacity and consent. If they feel at any point during the process the local authority is not acting in your relative's best interests, they are obliged to challenge this, including writing a report. The local authority is expected to provide a response.

A Care Advocate will support your relative to:

- Understand and be involved in the process, e.g. needs assessment, preparing a care and support plan, review of a care and support plan
- Communicate their views, wishes and feelings
- Understand their options and make decisions about their care and support
- Understand and secure their rights
- Appeal against a decision they are unhappy about

Watch advocates describe the role of a Care Act Advocate

Read a factsheet on Care Act Advocacy

Read Debbie's story

And this case study from the Advonet Group

The Care and Support Statutory Guidance states *"Many of the people who qualify for advocacy under the Care Act will also qualify for advocacy under the Mental Capacity Act 2005. The same advocate can provide support as an advocate under the Care Act as under the Mental Capacity Act. This is to enable the person to receive seamless advocacy and not to have to repeat their story to different advocates".*

The Care Act and Family Carers

One of the biggest changes under the Care Act is that family carers of an adult relative with care and support needs have the same rights as their relative. Here are 3 key rights you should know about:

1. A family carer will be entitled to an assessment if it is identified that they have their own care and support needs. The assessment must establish whether the family carer is willing and able to continue providing care to their relative and what impact this has on their wellbeing, day-to-day life, and ability to access education, training or recreational activities.

2. Family carers have the same rights to an assessment and support as their relative. Once a family carer's assessment has been carried out, the local authority will see which of the family carer's needs are eligible for support and will then produce a support plan to meet the family carer's needs.
3. Local authorities are under a duty to meet a carer's eligible needs, subject to financial assessment.

(Source: Mencap)

Click here to read more about family carers' rights under the Care Act

Further information

This guide from Hft provides information about the Care Act 2014 and other laws, for family carers of an adult with learning disabilities, autism or both: https://www.hft.org.uk/wp-content/uploads/2018/11/Hft-Care-act_artwork_17.pdf?utm_source=website&utm_medium=resourcesandguidance&utm_campaign=careact

This link takes you to resources from Irwin Mitchell including template letters to use to request an assessment for yourself or your relative: https://www.irwinmitchell.com/personal/protecting-your-rights/factsheets-and-template-letters

Watch this video clip from Hft including how to use the Care Act to challenge decisions about poor care and support: https://www.youtube.com/watch?v=MYAtjHPML_Q

Read Chapter 5 - Preventative support and safeguarding in line with the Care Act 2014 of the Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/422338/autism-guidance.pdf

The NICE Guidelines website: https://www.nice.org.uk

Read People's experience in adult social care services on the NICE Guidel- improving the experience of care and support for people using adult social care services for what you and your relative should expect during the assessment processes: https://www.nice.org.uk/guidance/ng86

Health and Care Act 2022

This section of the Family Carer Advocacy Pack covers the Health and Care Act 2022 and what it means for your relative and you (family carer).

What is the Health and Care Act 2022?

The Health and Care Act 2022 changes how health and care services are planned, co-ordinated, and commissioned (purchased and paid for). The reforms (changes) aim to promote better joined-up services, and mean that local authorities, the local NHS, and local partners will be expected to work together in 'Integrated Care Systems'.

Integrated Care Systems have been in development for a number of years and will now be formalised in law. An Integrated Care System (ICS) is made up of two parts.

- The first is the Integrated Care Board (ICB), which has responsibilities for the NHS functions of the ICS, including the NHS budget and commissioning (purchasing and paying for) NHS services.
- The second part, the Integrated Care Partnership, has responsibility for wider public health and social care needs and for developing an integrated care strategy, but it does not commission (purchase and pay for) services.

Provider Collaboratives are another new feature of the Health and Care Act 2022. Provider Collaboratives are partnerships that bring together NHS Trusts and non-NHS providers from voluntary, community and social enterprises (VCSE) or the private sector to look at how to collaboratively (work together to) improve the delivery of services and outcomes for the community they are in.

[Watch this video about Integrated Care Systems]

[Watch this video about provider collaboratives]

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The VCSE sector, is sometimes referred to as 'the Third Sector', 'Social Purpose Sector' or 'Civil Society'. It is made up of groups that are independent of the government, and they exist for the good of the community, to promote social, economic, environmental or cultural objectives to benefit society as a whole, or particular groups within it.

Read how CQC use Experts by Experience in their inspection process

What does this mean for your relative and you (family carer)?

You should expect:

- Services to be better coordinated because people with a learning disability, autism or both are typically supported by more than one service at a time
- A holistic approach to your relative's health because it is important that both their physical and emotional and mental health is addressed because one influences the other
- Health and social care professionals to work in partnership with third sector and private providers and involve agencies such as housing. This is because factors such as poor housing, lack of education and employment opportunities can contribute to both physical and emotional and mental health
- Working in partnership and coordinating services will make a better use of resources. This saving will be reinvested to provide better early intervention services in the community
- A legal duty to involve local residents, people who access services (your relative) their family carers (you) and other family members, in the design and delivery of integrated services. One of the ways this will be done is through the involvement of Experts by Experience
- Services available locally and close to home, including mental health services, e.g. assessment and treatment units
- Instead of success being measured by quantity, it will be measured by quality so instead of how many people have used a service, the focus will be on whether an intervention has had a positive impact, including being proactive in asking for and responding to feedback
- A big part of making services available locally will be identifying what is required to meet that area's specific needs to ensure that people receive the right support at the right time close to home.

A skilled workforce

As part of the Heath and Care Act 2022, from 1 July 2022, all registered health and social care providers (not just specialist services) must ensure that all their staff (including ancillary, e.g. cleaning staff and administrative e.g. reception staff) receive training in learning disability and autism, including how to interact appropriately. This should be at a level appropriate to their role. For example, a reception staff member needs some awareness training as they may come into occasional contact with a person with a learning disability or autism compared to a healthcare professional who would require a higher level of training.

The Care Quality Commission are responsible for ensuring that this happens,

Watch this video from SCIE showing how a young man was supported in a person-centred way to be involved in a decision about moving house and it will be part of their inspection criteria. If they identify that staff have not received training appropriate to their role to support people with a learning disability and autism, they may take regulatory action. Part of the Government's duty includes preparing and publishing a Code of Practice to set out what must be included in training to meet the legal requirement, including a public consultation.

Click here to read the Code of Practice

Many family carers and their relatives will have experience of using services which 'on paper' (e.g. via their website or brochure) state that they are *'learning disability and autism specialists'* but often find this *'specialism'* has not translated into the care and support and/or treatment their relative has received. The Act, and the duty on CQC to regulate this, means that going forward your relative should receive care and support and/or treatment from healthcare professionals who are well trained, knowledgable and skilled and if they are not then this can be raised as a concern or by making a complaint, including reporting to CQC.

Read more about the Oliver McGowan mandatory training on learning disability, autism or both. The training is named after Oliver, whose death shone a light on the need for health and social care staff to have better training on learning disabilities and autism, and has been campaigned for by his parents Paula and Tom McGowan:

Further information

Read this explainer from the King's Fund 'Integrated care systems: How will they work under the Health and Care Act':
http://www.kingsfund.org.uk/publications/integrated-care-systems-explained

Autism Act 2009

The Autism Act which was introduced in November 2009. The Act placed a legal duty on the Government to have an autism strategy and statutory guidance for local authorities and the NHS to improve services for autistic adults. Written into the Act was a commitment to monitor progress and identify where further action was required.

Fulfilling and Rewarding Lives

The Strategy for Adults with Autism in England was published in March 2010 and set out 5 key actions and recommendations:

1. Increasing awareness and understanding of autism
2. Developing a clear and consistent pathway
3. Improving access to the services and support people need to live independently within the community
4. Helping adults with autism into employment
5. Enabling local partners to develop relevant services to meet identified needs and priorities

Click here to read Fulfilling and Rewarding Lives

The strategy included the following statement:

> “*The Government’s vision for transforming the lives of and outcomes for adults with autism: All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents.*”

For adults with autism, this means:

- Having a right to receive an assessment of need from social services
- Getting the same opportunities for education and further education
- Being supported to get a job and stay in work
- Being able to choose where to live - just like anyone else
- Having relationships and social networks

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- Having their health needs properly met in a way which is appropriate for someone with autism
- Being safe from hate crime and discrimination
- Living in a society where people understand, respect and accommodate difference, receiving support to live independently, as appropriate

The Act strengthens and reinforces other acts such as the Human Rights Act, the Equality Act, the Care Act and the Children and Families Act. Whilst the Act is just for adults, updated strategies and statutory guidance now cover children and young people. This move is in recognition of the importance of receiving the right support as early as possible and across the lifetime. The Act has always included people with a learning disability who are autistic.

Updates to the strategies

In 2014 an updated strategy was published: 'Think Autism Fulfilling and Rewarding Lives, the strategy for adults with autism in England - an update' and in 2015 the statutory guidance for local authorities and the NHS was updated and published.

The update included all the original key actions and recommendations with some additions. The full list is:

- Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services
- Planning in relation to the provision of services for people with autism as they move from child to adulthood (transition)
- Local planning and leadership in relation to the provision of services for adults with autism
- Preventative support and safeguarding in line with the Care Act 2014
- Reasonable adjustments and equality
- Supporting people with complex needs, whose behaviour may challenge or who may lack capacity
- Employment for adults with autism
- Working with the criminal justice system

Read Think Autism

Read the statutory guidance for local authorities and NHS organisations

The national strategy for autistic children, young people and adults

The latest strategy also makes a commitment to building the right support in the community and supporting people in inpatient care. It states:

> “*We will achieve the targets set out in the NHS Long Term Plan to reduce the number of autistic people and people with a learning disability being admitted into inpatient mental health services. We will do so by improving the treatment of autistic people in mental health legislation to prevent people from being avoidably admitted to inpatient care and improving the provision of community mental health and crisis support. We will also improve the suitability and availability of housing support and social care. In addition for people who do need to be in inpatient mental health settings, the quality of care will be better and more tailored to their individual needs and people will be discharged back into their communities as soon as they are well enough to leave*”

Read the Government's latest national strategy for improving the lives of autistic people and their families in England

Some family carers and/or their relatives still struggle to get an autism diagnosis. Without a diagnosis it can be a challenge to access services, especially in the current climate where there are limited resources. The Autism Act, Autism Strategy and Nice guidelines are all clear about the assessment process for autism.

Follow this link to the National Autistic Society website for a timeline of what has been achieved since the introduction of the Act

If a person has one or more of the following:

- Persistent (ongoing) difficulties in social interaction
- Persistent (ongoing) difficulties in social communication
- Stereotypic (rigid and repetitive) behaviours, resistance to change or restricted
- interests, and

one or more of the following:

- Problems in obtaining or sustaining education or employment
- Difficulties in initiating (starting) or sustaining (continuing) social relationships
- Previous or current contact with mental health or learning disability services
- A history of a neurodevelopmental condition (including learning disabilities and attention deficit disorder) or 'mental disorder'

Read Autism spectrum disorder in adults: diagnosis and management (NICE guidelines)

If two or more of the above are present, then a comprehensive assessment which includes diagnostic, risk and needs assessments should be offered. You (family carer) or your relative can ask your GP or another healthcare professional (e.g. speech and language therapist, occupational therapist) for a referral for a comprehensive assessment.

Your local authority has a legal duty, through the Care Act, even if you and your relative are assessed as not being eligible for support, to provide information about the organisations, services etc. available in your area.

Further information

Organisations which can offer you and your relative support:

National Autistic Society: https://www.autism.org.uk/

Autism Alliance UK: https://www.autism-alliance.org.uk/

Ambitious about Autism: https://www.ambitiousaboutautism.org.uk/

The Challenging Behaviour Foundation (if your relative also has a severe learning disability and displays behaviour described as challenging): https://www.challengingbehaviour.org.uk/

Supporting Family Carers in their Role

Family carers play an important and essential role in ensuring that their relative is appropriately supported, receiving all their entitlements, and having their rights respected. This section of the Family Carer Advocacy Pack provides information about what is available to family carers to support and enable them to remain in their role for as long as they want to, and at a level they want to.

NHSE defines family carers as:

> ***Anyone, including children and adults who look after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid.***

Even if your relative is no longer living in your home, you can still be a family carer, have the same level of involvement, be advocating on their behalf formally e.g. as their nearest relative or because they have been assessed as lacking capacity for a certain decision at a certain time or informally. However, the level of involvement you, and your relative, decide is entirely your choice. Professionals should never encourage or discourage your involvement, make you feel guilty or force you into taking on anything you don't want or feel able to.

Share the load

Acknowledge the challenges and don't be afraid to ask for help. This does not mean that you are not a good family carer. Think about all the roles you carry out for your relative, for example care and support coordinator, communication facilitator, behaviour support analyst. You will be doing this without formal training and unpaid compared to the professionals involved in your relative's life who have chosen their role as a job.

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> ***For parents… the overriding sense is of their being isolated, excluded and left to get on with a task which is too difficult or beyond the expertise of qualified professionals.***
> McGill et al, 2005

Who can help

- **Other family members.** More than one family carer may be involved in the care and support of your relative e.g. both parents and/or other family members may be taking the lead e.g. siblings, grandparents, aunts and uncles or cousins.
- **Friends.** Maintaining friendships can be a challenge when you are short of time but making time for yourself will benefit your emotional and mental health which in turn will support your physical health. Although it is helpful to have friendships which allow you to share your experience of being a family carer it can be beneficial to have friendships which allow you to be a person independent of this responsibility.
- **Other family carers.** Family carers report that it is often other family carers who are the best source of support and information about local support groups.
- During Covid many charities offered **family support online** using Zoom for example. For some family carers online support continues to be easier to access, e.g. it eliminates the need for travel, they can take advantage of support further afield. The success of this has encouraged many organisations to continue to offer this type of support.

You can find out about local groups using the Carers Trust search facility

You can find out about the peer support offered by the CBF

- There are **charities** which offer families support nationally and locally if their relative has a specific diagnosis, e.g. Down’s Syndrome Association, Fragile X Society, National Autistic Society.
- Support can be accessed through **social media** including accessing general information by following a particular Facebook page or joining a closed group which allows family carers to ask questions, contribute to discussions.
- Ask **the service your relative uses** what support they provide for family carers.
- Identify one or two **professionals** who you trust, have a good relationship with and understand your relative’s and your family’s needs. They can act as allies in meetings, when you feel that your voice is not being heard.
- Having to regularly make decisions on behalf of your relative can be stressful. To share this responsibility you could set up a **Circle of Support.**
- Check what **Professional Independent Advocacy** your local authority funds for family carers. In some circumstances you have a statutory right, e.g. if you are having a carers assessment and are finding the process difficult.

What are your rights as a family carer?
Read this guide ‘the Equality Act 2010: What do I need to know as a carer’. It explains how the Equality Act offers protection to family carers and includes case studies:

The Care Act 2014

> *The Care Bill in many respects marks a quiet revolution in our attitudes towards, and expectations of, carers. At last, carers will be given the same recognition, respect and parity of esteem with those they support. Historically, many carers have felt that their roles and their own well-being have been undervalued and under-supported. Now we have a once in a lifetime opportunity to be truly acknowledged and valued as expert partners in care.*
>
> Dame Philippa Russell, Chair, Standing Commission on Carers

The Care Act 2014 puts your rights as a family carer on an equal footing as your relative’s entitling you to an assessment in your own right which considers the impact of your role as a family carer on your wellbeing.

Wellbeing includes:

- Personal dignity
- Physical and emotional and mental health
- Protection from abuse and neglect
- Control over your day-to-day life
- Ability to participate in work, education, training or recreation
- Social and economic wellbeing
- Domestic, family, and personal relationships
- Suitability of living accommodation
- Your contribution to society

Carers UK has a list of frequently asked questions - and answers - about the Care Act

There is more information here from Disability Rights UK about the assessment process

Developing your skills and knowledge

- NICE guidelines recommend that family carers should have the opportunity to develop their skills and knowledge through training. They highlight that any training should provide a balance between learning, enjoyment, a chance to meet other family carers and opportunities for peer support.
- Read the self-advocacy guide from Carers UK which has been developed to help family carers to understand their rights, communicate effectively with professionals and recognise how to be heard.

Read more about the NICE guidelines here (para 1.6.4-1.6.9)

Click here to read the Carers UK self advocacy guide

- Jointly is a mobile and online app created by family carers for family carers. It is free to download onto most mobile phones and aims to make the administration tasks related to caring a little easier, less stressful and more organised. It combines group messaging with other useful features including to-do and medication lists, calendar and more.

Click here to access the Jointly website

Your physical, emotional, and mental health

- Family carers are often guilty of neglecting their own health needs. Read this report from Bringing Us Together which highlights how lack of time and prioritising other commitments e.g. their relative and other family members' needs and work commitments contribute to symptoms including stress, anxiety, depression, and tiredness.

Click here to read the report from Bringing us Together

- Register with your GP surgery as a family carer. You are entitled to reasonable adjustments as a family carer, for example the time and length of appointment.
- You will be prioritised for annual flu vaccinations and Covid boosters.
- Read what NICE guidelines say should be in place to support family carers in their role including access to psychological interventions, e.g. counselling to support emotional and mental health and the types of reasonable adjustments they expect to happen.

Read the NICE guidelines on supporting adult carers

Financial support

Being a family carer can result in costs which are not covered by your relative's benefits (e.g. replacing equipment due to behaviour described as challenging, adapting your family home, and having to cover the costs personally) or you may find yourself unable to work part or full time because of a lack of support services, if your relative is in crisis and you are trying to resolve the situation.

- Use this online benefits calculator from the Carers Network to check whether you are receiving all your entitlements

Click here for the benefits calculator from the Carers Network

This link provides information about grants and discounts which you can apply for either yourself or your relative

- If your relative is struggling with their finances because of their mental health, they can ask for a referral to the Mental Health Crisis Breathing Space service.

Find out more about the Mental Health Crisis Breathing Space service

- Be strict about what you take on for free. Family carers are often asked to contribute to consultations, reports, develop training for professionals all in the name of inclusion or co production but this is only the case if you are treated as an equal, e.g. paid for your time.

Further information

Carers Trust https://carers.org/

Carers UK - Information about Carers UK local directory, helpline, and online forum which all help connect family carers with others who understand what they are going through – "We're here to make sure no-one has to care alone". http://www.carersuk.org/help-and-advice/get-support

Information about being a family carer http://www.carersuk.org/help-and-advice/guides-and-tools/looking-after-someone-guide/

Information about flexible working http://www.carersuk.org/help-and-advice/work-and-career/your-rights-in-work/flexible-working-videos/

The Challenging Behaviour Foundation
Detailed information sheet about the impact of being a family carer
http://www.challengingbehaviour.org.uk/wp-content/uploads/2021/02/012-Impact-of-caring-on-families.pdf

The CBF offer peer support and 1:1 Listening Ear calls hosted by family carers. If your relative has a severe learning disability and behaviour described as challenging, please email support@thecbf.org.uk for further information.

Information about peer support https://www.challengingbehaviour.org.uk/for-family-carers/peer-support/

In addition there is the option of joining the CBF's Family Carers Email Network. The email network allows family carers to ask questions, share experiences, offer practical solutions to everyday problems such as how to fill in a benefits form
http://www.challengingbehaviour.org.uk/for-family-carers/family-carers-email-network/

Information about family carer wellbeing and resilience
http://www.challengingbehaviour.org.uk/information-and-guidance/wellbeing-of-family/family-carer-well-being-and-resilience/

Information on the Mind website explaining what resilience is
http://www.mind.org.uk/information-support/types-of-mental-health-problems/stress/managing-stress-and-building-resilience/

Bringing Us Together (BUT)
BUT regularly offer focused sessions for family carers on topics such as how to manage anxiety and feeling overwhelmed, local authority charging policies and how to claim disability related expenditure. They are also running Peer Advocacy courses for family carers who are in a position to advocate for other family carers. Email katie@bringingustogether.org.uk for further information.

The Disability Benefits Consortium (DBC)
The Disability Benefits Consortium (DBC) is a national coalition of over 100 different charities and other organisations committed to working towards a fair benefits system. Using their combined knowledge, experience, and direct contact with people with a disability and family carers, they campaign to ensure Government policy reflects and meets the needs of everyone with a disability.

Disability Benefits Consortium website http://disabilitybenefitsconsortium.com/?_ga=2.86669791.63355522.1670251970-376828313.1670251970%2F

National Autistic Society's information on the support available for family carers
http://www.autism.org.uk/advice-and-guidance/topics/social-care/social-care-england-carers/support-available-for-carers

Sibling Support
Sibs is a charity which provides support to siblings of relatives who have a disability.
Sibs website: http://www.sibs.org.uk/

Parents often hand over the role of main family carer as they get older. Read a sibling's perspective here: https://www.challengingbehaviour.org.uk/news/a-siblings-perspective/

Contact (For families with disabled children)
This page provides links to information about support (1:1 listening ear service) and finance (benefits): http://contact.org.uk/help-for-families/faqs/

Mind
Information for family carers about:

- recognising difficult feelings related to being a family carer
- tips on how to look after yourself
- coping with and information about a specific diagnosis
- social care rights of family carers

http://www.mind.org.uk/information-support/helping-someone-else/carers-friends-family-coping-support/

Strengthening your role as a family carer

This section of the Family Carer Advocacy Pack is about the ways you can strengthen your role as a family carer.

As a family carer, you have certain rights and responsibilities in relation to your relative until they reach the age of 16 years old or over. In law this is known as parental responsibility. You can make decisions on their behalf on a wide range of issues. However, as soon as your relative turns 16 years old or over parental rights and responsibilities change, even if your relative lacks the mental capacity to make decisions themselves.

If you still want to be involved in key decisions about your relative and strengthen your role as a family carer there are several ways to do this.

Deputyship

A Deputy is legally responsible for someone who has been assessed as lacking the capacity to make decisions for themselves. A Deputyship Order will set out the Deputy's powers (and limits). They may relate to your relative's:

- Finances, property or accommodation, e.g. where they live, how they are supported
- Medical treatment and other health care issues
- Personal welfare

The powers given will depend on your relative's needs. A Code of Practice sets out how a Deputy should undertake their role.

Click here to read the Code of Practice which sets out how to be a Health and Welfare Deputy

Click here to read the Code of Practice which sets out how to be a Property and Affairs Deputy

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There are two types of Deputyships:

Deputy for Property and Financial Affairs

Examples of when a Deputy for property and financial affairs may be necessary are:

- To sign a tenancy agreement to rent a property
- To enter into a mortgage agreement to buy a property
- To pay bills or organise a pension

If your relative's only income is from social security benefits and they have no property or savings you are unlikely to need to apply to be a Deputy, instead you can become an "Appointee". The application process for this is quicker and easier.

Deputy for Personal Welfare

Examples of when a Deputy for Personal Welfare may be necessary include:

- A series of linked decisions over time is required e.g. a series of decisions relating to a
- Medical condition
- There is a history of serious family disagreements over welfare issues
  Your relative is living in supported living accommodation and there is a need to be clear about their capacity to refuse or invite people into their home

Mental Capacity Act Code of Practice

If the Mental Capacity Act Code of Practice is followed then Deputies for personal welfare should only be required in the most difficult of cases. The expectation is that health and social care professionals and family carers should be able to work in partnership to settle matters between them using the best interest process. If not, then a stand-alone application can be made to the Court of Protection.

Best interests is a way of considering the views of a person who has been assessed as lacking capacity and considering what the best option is for them. When making a decision on behalf of someone else consideration should be given to their likes, dislikes, wishes, feelings, values and beliefs, how they can be supported to be involved and the views of others e.g. family carers, other family members and friends.

Does a Deputy make all decisions?

No. Under the Mental Capacity Act your relative is assumed to have mental capacity to make decisions (even unwise ones). However a Deputy can make the more difficult decisions where your relative has been assessed as lacking capacity such as agreeing to medical treatment, medication changes, or where your relative lives. The most important thing is that any decisions are made in your relative's best interests.

Who can be my relative's Deputy?

Any adult aged 18 years old or over can be appointed as a Deputy if they meet a number of conditions such as not having a criminal record or not being declared bankrupt.

There are two types of Deputies:

- Lay/non professional, e.g. a family carer or friend or
- Professional/panel e.g. a solicitor who is chosen by the Court from a list of approved people

How to become your relative's Deputy for either Property and Financial Affairs, Personal Welfare or both

You need to make an application to the Court of Protection and pay a fee. The Court's role is to make decisions regarding the property, financial affairs and personal welfare of people who have been assessed as lacking the mental capacity to make those decisions for themselves. The Court appoints Deputies to make day-to-day decisions on behalf of someone who has been assessed as lacking capacity and considers one-off applications regarding complex or contentious (because someone disagrees) decisions.

'Deputies: make decisions for someone who lacks capacity' provides information about the application process

Do I need a solicitor?

You do not need to 'instruct' a solicitor to make an application for Deputyship, but some family carers find the process complicated and long-winded. A specialist solicitor will be able to provide legal advice and guidance. They will ensure that the application is completed properly and that the people who must be notified about the application are told in good time. If the application is contentious (because someone disagrees) and you have to go to Court, then you will benefit from legal representation at any hearings. Instructing a solicitor will involve a fee.

The whole process can take up to 16 weeks and if you are approved the court order will inform you what your role involves. This will include:

Making regular reports to the Office of the Public Guardian, to show that you are acting in your relative's best interest. You should keep records of decisions such as:

- Making a major investment
- Changing the care your relative is getting
- Deciding where your relative should live

You will be expected to keep and provide copies of any documents relating to decisions you've made, for example:

- Receipts
- Bank statements
- The court order will also provide details of the types of decisions you're allowed to make and you will be required to report on all decisions made

Involving your relative in decision-making

As your relative's Deputy you should always consider what decisions your relative can make, when well supported.

For example, if your relative is able to make day-to-day financial decisions about what to buy on a shopping trip, then they could possibly make other small spending decisions. If they are more alert in the morning then this may be the best time to involve them in decision-making, rather than later in the day.

As your relative's Deputy you cannot:

- Restrain your relative, unless it is to stop them coming to harm
- Stop life-sustaining medical treatment, e.g. turn off a life-support machine
- Make a will for your relative, or change their existing will

- Make large gifts from your relative's money
- Hold any money or property in your name on your relative's behalf. However, a
- Deputy can use the Court Funds Office, or a bank or building society account to help someone with their finance

How long does my role as Deputy last

A Deputy's role can end or be cancelled for a number of reasons including:

- Deputyship orders are granted according to the specific needs of your relative and do not usually have an expiry date. If a time limit is considered appropriate this will be set out in the order and when it expires a reapplication can be made. At this point a new Deputy can also apply for the role.
- The Court of Protection ends the Deputy's role because it feels the Deputy has not been acting in the person's best interests. In this instance the Court of Protection will appoint a new Deputy.
- Your relative no longer needs a Deputy's help, e.g. the status of their mental capacity has changed.
- Your relative dies. The Deputy must provide this information to the Office of the Public Guardian as soon as possible. The Deputy may have to provide a final report about their decisions and financial transactions.
- The Deputy Dies. In this instance the Court of Protection will only appoint a new Deputy:
    - If your relative still needs a Deputy
    - Someone else applies to be the Deputy
    - The court can appoint a Panel Deputy or a local authority Deputy if no one else applies for the role

The cost of becoming your relative's Deputy will depend on individual circumstances.

Read this information from the Office of the Public Guardian (OPG) about how to get help with paying fees

This CBF information sheet, including a case study, is about a family's experience of applying for deputyship and the positive difference it made

The OPG publication 'Making decisions… about your health, welfare or finances. Who decides when you can't', provides further information

Appointeeship

If your relative has been assessed as not having the mental capacity to manage their own benefits or finds it difficult, for example because they find it hard to fill in forms or manage financial information, then you can apply to the Department of Work and Pensions (DWP) to become their appointee. As your relative's appointee you can claim and manage their benefits and access information from the DWP in relation to their benefits.

To become your relative's appointee you must contact the DWP. They will arrange to visit your relative to assess if an appointee is needed, and whether you are a suitable appointee. If your application to become your relative's appointee is successful, the DWP will send you documentation to confirm that you are formally your relative's appointee. You are not the appointee until you have received this form. It is important to note that appointeeship only relates to managing your relative's benefits.

This link provides information about how to become an appointee

There is a different process for tax credits.
Read 'Claiming and dealing with tax credits for someone else' for further information

Appointeeship v Deputyship – a family carer's story

I am my daughter's appointee but found it increasingly difficult to get people to accept this when it comes to discussing utility bills, accessing online banking, even sorting out a bus pass. Each organisation wanted proof of Deputyship.

The ex-manager of my daughter's service decided to remove personal money from individual flats and keep it in the main office where only 3 staff had access to it. This meant my daughter was restricted in what she could do, e.g. if the manager or 3 members of staff were not around, she didn't have access to her money so couldn't decide on the spur of the moment to go shopping, for a coffee, to the cinema. This could result in behaviour described as challenging.

It wasn't fair on my daughter or her support staff. When I queried this, I was told I could not alter this as it was CQC approved – this is not true – and I had no say over her accounts because I did not have Deputyship and being her Appointee did not count. A couple of safeguarding queries sorted this, and the manager moved on. I decided that to avoid this type of thing happening again I would apply for (and was successful) for Deputyship and have found things much easier.

Litigation Friend

A 'litigation friend' is someone who acts on behalf of someone else to enable them to access the justice system on an equal basis, for example a court case relating to:

- A civil case, except a tribunal
- A family case
- A Court of Protection case

Who can be appointed a litigation friend There are two groups of people who can be appointed as a litigation friend. The first is a person with authority as a Deputy to conduct the proceedings on behalf of the protected party (your relative). If there is no appointed Deputy, then an appropriate adult (this could be you) can put themselves forward as a litigation friend. You will need to meet certain criteria:

- You can fairly and efficiently conduct proceedings on behalf of the protected party (your relative)
- You have no interest adverse to that of the protected party (your relative) and
- You undertake to pay any costs which the protected party (your relative) may be ordered to pay in relation to the proceedings subject to any repayment they might be entitled to

More information about litigation friends

Lasting Power of Attorney

Lasting Power of Attorney is when a person gives their consent to someone else to make decisions on their behalf, for example if they become ill or have an accident that temporarily or permanently impacts on their ability to make decisions for themselves. This could apply to your relative if they are able to make decisions independently now but have concerns about the future, e.g. if your relative has Down's Syndrome and is worried about developing early onset dementia.

Read this information from Mencap for people with a learning disability, autism or both and their family carers about applying for lasting power of attorney

Working in Partnership - Family Carers and Professionals

This section of the Family Carer Advocacy Pack is about how family carers and professionals can work together, and overcoming some of the barriers to this.

Twenty years ago The Valuing People paper (March 2001) acknowledged the unique and important role of family carers:

> ***"…..Caring for a family member with a learning disability is a lifelong commitment, which continues even when the person is living away from the family home. Carers make a vital contribution to the lives of people with learning disabilities, often providing most of the support they need. They are a crucial resource for ensuring that people with learning disabilities can live in the community."***

In 2020 the important role of family carers was recognised and highlighted again. Baroness Hollins, Chairperson of the Independent Care (Education) and Treatment Review (IC(E)TR) programme for people with a learning disability and autistic people in inpatient settings wrote

> ***"Families are being excluded in several ways, and in most cases, they are not being recognised as essential members of the team responsible for ensuring the person's best interests are being met. They are excluded from receiving regular information and updates about the care of their family member, being unable to check that their relative is safe and being prevented from talking to or visiting them regularly, even though when they do visit, they provide comfort and reassurance to their detained relative. Many family members would welcome recognition of their own need for support, both during an admission, but also after discharge when they see more closely the long-term consequences for their relative of being a victim of a dysfunction system ….."***

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One of her recommendations following the thematic review of Independent Care (Education) Treatment Reviews included ***"to listen to patients and families, put them at the centre of care planning and ensure skilled and appropriate representation and advocacy".***

Read the full letter here

Policy and best practice promote the need to work in partnership with family carers and in some cases, it is the law, such as in the Mental Capacity Act 2005 and the Care Act 2014. It is one of the key lines of inquiry for CQC inspections:

> ***Are people's carers, advocates and representatives, including family members and friends, identified, welcomed, and treated as important partners in the delivery of their care?***

Despite this, family carers often experience barriers when trying to work in partnership with health and social care professionals to achieve the best outcomes for their relative. These include:

The system

- A 'crisis management' approach. For example addressing one issue then discharging which does not provide the opportunity to develop a positive working relationship
- Having to fight to access services/support
- Being promised something and it not being delivered
- Frustration at lack of progress and how long things take to happen or change. For example discharge from mental health services
- Lack of joined up working resulting in family carers often taking on the role of 'key worker' or having to retell their relative's 'story' over and over

Lack of understanding from professionals about the role of family carers

- Not familiar with the rights of family carers to be involved in the care, support and/or treatment of their relative, instead labelling them as overprotective, difficult or interfering
- Not treating family carers as equal partners which can result in them feeling that their involvement is a 'token gesture'
- No consideration given to making reasonable adjustments. For example, use of jargon, services being inflexible to the needs of families when planning meetings, cultural needs
- Professionals not used to being questioned or challenged which can result in family carers being considered obstructive, uncooperative, difficult and being excluded going forward

Family carer needs and experience

- Impact of tiredness, exhaustion, own physical, emotional, and mental health needs
- Not feeling listened to
- It is difficult to maintain a positive relationship with health and social care professionals who are not providing good quality care, support and/or treatment, may be presenting a barrier to discharging your relative, or involved in a safeguarding incident
- Professionals making assumptions or judgements about families, e.g. level of involvement a family carer should have in their relative's care, support and/or treatment

- Other responsibilities (caring and work related)
- Resentment – a family carer is likely to be the only person in a meeting, representing their relative, who has had to pay their own travel costs and is not being paid for their attendance
- Being included until there is a difference of opinion

Professionals experience their own barriers, including:

- Limited resources
- Heavy caseloads
- Lack of appropriate local services
- Time constraints
- Mistrust from families (because of past experiences)
- Limited access to training about working in partnership
- Being the bearer of bad news but not the person responsible for the decision
- Other health and social care professionals not working in partnership
- Fear of raising expectations and then not being able to deliver

What can family carers do to overcome some of the barriers

- Be clear about what level of involvement you want, and it can vary depending on you and your family's needs. It is your choice. You are not obliged to attend meetings, but this does not prevent you being kept up to date, receiving reports, contributing to meetings via a letter or email.
- Good communication
    - Keep communication channels open
    - Respect each other's point of view, even if there is a difference of opinion
    - Listen and reflect first before making any decisions
    - Be honest, if you don't understand something say so, ask for information in a different format, jargon free etc.
- Understand the challenges each other faces
- Acknowledge each other's expertise
- Know your rights as a family carer under Acts such as the Equality, Mental Capacity or Care
- Ask health and social care professionals to be clear about their role and responsibilities, what they will be doing and by when
- Be honest about your past experiences positive and negative, e.g. "I find it difficult to trust health and social care professionals because previously ….." Hopefully those you are currently working with will acknowledge this and provide reassurance
- Remind health and social care professionals, when necessary, that everyone's focus should be on positive outcomes for your relative
- Provide feedback – good and bad – and don't be afraid to raise a concern or make a complaint. Some health and social care professionals may encourage and

support you to raise a concern or make a complaint because they may be as frustrated as you at the lack of resources or the way in which they are required to work

- Identify an ally but remember to maintain boundaries, e.g. don't become over friendly or too reliant on one health and social care professional
- Ask the health and social care professionals/ organisations you are working with if they have a 'working in partnership with family carers' policy and if yes, request a copy

Visit the Challenging Behaviour Foundation Working in Partnership section and watch Sharon (family carer) and Roger Banks (psychiatrist) talk honestly about the barriers and solutions to working in partnership.

"It isn't a battle to be won… It's about working out the best solution collaboratively (together) for the person (your relative)…"

Family carers regularly have to represent their relatives in meetings. Read these ten top tips about what you can do and what should happen:

1. Be prepared. Read through the notes from any previous meetings, check any outstanding actions, make sure you know where the venue is. If it is convenient, it is always better to have meetings in a neutral space. Meetings held in your home can put you under pressure, e.g. offering refreshments, feeling that you must tidy up before the meeting.
2. Request all documents related to the meeting be shared in advance (ideally a minimum of 48 hours) such as the agenda (things to be discussed) or individual reports from health and social care professionals. If you have anything you would like discussed at the meeting, ask if this can be added to the agenda. You are also entitled to submit a report.
3. Confirm your attendance and ask for confirmation about who else will be attending. For example, if the meeting is about your relative's discharge from a mental health service and the current barriers are adult social care funding and housing but nobody from these organisations will be attending, challenge whether it should be rearranged.
4. You are entitled to ask if certain health and social care professionals can be invited to meetings, if you think their attendance will benefit your relative.

   At the start of the meeting, pass round a piece of paper and ask everybody to write down:
   - Their name
   - Their role
   - Their contact details, including an email address. Having an email address means you can make contact at a time convenient to you. If you are unable to make contact via telephone you have an alternative and you have a paper trail of any requests you have made, etc. in case you have to raise a concern/make a complaint at a later date

    - Whether they have met your relative or not. They can just write yes or no. This helps you consider the usefulness of somebody's involvement, e.g. if they are employed by the service as an activities co-ordinator but haven't met your relative, how do they know what their interests are.
    - Add your details to the top of the list so that if anybody wants to make a note they can.
5. It can be difficult to take notes and pay attention to what is being said. Confirm at the beginning of the meeting that there will be notes taken. This will leave you free to participate fully in the meeting, able to ask questions, challenge something if you disagree.
6. It is always better to stay calm in meetings, but this is easier said than done, e.g. if you think somebody is preventing your relative's discharge from a mental health service or is responsible for managing a staff team which has been providing poor care, support and/or treatment.
7. Ask for any actions to be recorded separately and ensure that each action is assigned to somebody with a completion date. Make sure you receive a copy of this.
8. Keep a folder for all your relative's documents, e.g. notes of meetings, reports, print out any emails you may need to refer to in a meeting.
9. Don't be afraid to ask for reasonable adjustments, e.g. timings of meetings, use of language which is jargon free. If you think that you will find a large meeting intimidating (frightening) ask for less people to attend and another professional can update them afterwards.
10. Ask a friend to accompany you for support or check whether your area offers a family carer advocacy service. You can also contact a relevant charity organisation, e.g. the Citizens Advice Bureau. Whilst they may not be able to attend a meeting alongside you, they may be able to offer advice and help you plan

Read this self-advocacy guide from Carers UK which has been developed to help anyone with caring responsibilities gain confidence to understand their rights, communicate effectively with professionals and recognise how to be heard:

Click here to read the guide

Click here to access a toolkit

Triangle of Care

The Triangle of Care is a project which brings together family carers, their relatives and professionals. was launched in July 2010 by The Princess Royal Trust for Carers (now Carers Trust) and the National Mental Health Development Unit to highlight the need for better involvement of family carers in the planning of their relative's care, support and treatment when they are admitted to a mental health service.

What does being a member mean?

When a a mental health trust joins the Triangle of Care scheme, it is recognising the importance of involving and supporting family carers. It does this by completing a self-assessment for all its services in partnership with family carers. It then works on what needs to change to ensure family carers are a core part of the trust. As a requirement of membership, mental health providers must have family carer partners who act as critical friends to the process. The six key standards that must be met to fulfil the Triangle of Care membership include:

1. Family carers and the essential role they play is identified as soon as possible e.g. services are proactive at engaging with family carers when their relatives are admitted.
2. Staff are 'family carer aware' and trained in family carer engagement strategies.
3. Policy and practice protocols (rules) about confidentiality and information sharing are in place - the right information is shared at the right time with the right people.
4. Defined post(s) responsible for family carers are in place, e.g. Family Carer Champions.
5. A family carer introduction to a service and staff is available, e.g. information pack for family carers.
6. A range of family carer support services is available.

How the Triangle of Care can help your relative

If services are members of the Triangle of Care, they will actively look to work in partnership with you. As a family carer you are likely to be the person who has always been involved in your relative's life. You have unique knowledge about your relative e.g. their early years, the types of services they have used from education through to the current time, what has worked well and what has not, what support they need day to day.

Read the Carers Trust 'Guide to the Triangle of Care'

Family Carer Involvement Contract

Some services draw up a family carer involvement contract. This is developed in partnership with the service and family carer(s) and details, for example, how communication will take place, the level of involvement family carers would like. You can ask the service your relative uses about this and even if they don't have a formal process in place, it is worth discussing and establishing how you will work together to ensure the best outcomes for your relative.

You can also discuss this with whoever commissions (pays for) your relative's care and support and/or treatment to confirm that the service your relative uses values the role of family carers. If you feel this is not happening, you can raise it as a concern or make a complaint.

Family Care Involvement Contracts should not be used as a way to limit family carer involvement or contact with their relative.

Further information

Read this guidance from Skills for Care for adult social care employers when working with family, friends and carers: http://www.skillsforcare.org.uk/resources/documents/Developing-your-workforce/Care-topics/Working-with-families/Working-with-families-friends-and-carers-A-framework-for-adult-social-care-employers.pdf

Watch these 2 videos from NHS England about best practice when working in partnership with family carers whose relatives are using a secure mental health service:

1. http://www.youtube.com/watch?v=4uFUV8HecRU
2. http://www.youtube.com/watch?v=433TPVR1K7I

Read the CBF's 'Broken' report which includes the experience of family carers and how continuously having to fight for services/support contributes to their trauma:
http://www.challengingbehaviour.org.uk/news/broken-report/

All CBF training promotes partnership working. Read more here:
http://www.challengingbehaviour.org.uk/workshops/workshops-the-benefits/

Information Sharing, Confidentiality, Whistleblowing and Freedom of Information

This section of the Family Carer Advocacy Pack outlines confidentiality in health and social care, the legal frameworks underpinning it and how this impacts on your role as a family carer supporting your relative.

What is confidentiality

Confidentiality is about protecting a person's privacy. This means personal information should only be shared when consent has been given, it is in a person's best interests, and it is necessary to provide care and support and/or treatment.

Professionals in health and social care should act in accordance with confidentiality principles to protect your relative's right to privacy, but sometimes this information will need to be shared, particularly with yourself or others involved in your relative's care.

The Human Rights Act and information sharing and confidentiality

Article 8 of the Human Rights Act is the right to a private and family life. It includes:

- Respect for private and confidential information and how this is stored and shared (in the UK this is covered by the Data Protection Act 1998)
- The right to control how information about your private life is shared

This right is a qualified right which means there may be instances when it does not apply.

Read this information about Article 8 of the Human Rights Act: Respect for private and family life

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Sharing information with family carers

> “*Carers need to be given sufficient clear information to help them provide more effective care - offering information to carers about care, support plans, medication, and giving them advice about ‘what to do in a crisis’, does not amount to breaking confidentiality.*”

If your relative has been assessed as having the capacity to consent to sharing their personal information, ealth and social care professionals should discuss with them:

- How they would like their family involved in their care, support and/or treatment
- Agree what information they are happy to share, with who and when
- The advantages of sharing information, and how it can be of benefit in particular situations. For instance, if you (family carer) are responsible for helping your relative with their medication, you will need to know information about what the medication is, what it is for, dose, side effects to look out for and whether it is helping or not.

If your relative has been assessed as having the capacity to consent to information sharing and states they do not want you or other family members involved in their care and support and/ or treatment, health and social care professionals may still share information, e.g. to help understand your relative's diagnosis, proposed treatment, or care and support needs on discharge.

Discussions about sharing information should take place more than once with your relative to give them the opportunity to change their mind.

If your relative is assessed as lacking the capacity to give consent to share information, then the principles of best interests should apply.

> “*Confidentiality should not be used as a reason for not listening to carers, nor for failing to discuss fully with individuals the need for their family and friends to receive information so that they can continue to support them*”
>
> Department of Health: Developing services for carers and families of people with mental illness, November 2002

Read this fact sheet by Rethink Mental Illness for family carers about confidentiality and information sharing. If your relative has capacity to consent to share information, then the Rethink template for providing consent may be useful. You can keep a copy and your relative can ask for a copy to be kept in their records

Breaching confidentiality

On occasions health and social care professionals may breach your relative's confidentiality and share information

- When it is in the public's (e.g. the police think your relative might be a risk to other people) or your relative's (e.g. safeguarding) interests
- When a court or legislation (the law) says they have to

A professional should tell your relative if they need to breach their confidentiality through a court order unless it would place your relative or other people in danger.

If a professional breaches confidentiality without good reason they may be breaking the law and your relative could take legal action against them.

All information shared about your relative should be accurate and up to date. You can help with this by ensuring:

- That all plans (e.g. communication passport) include:
    - a date on them (e.g. last reviewed on [date])
    - the names of the people involved in developing the plan
    - if your relative has capacity, who they have agreed to share the plan with or
    - if your relative has been assessed as not having capacity for this decision what is in their best interests
- Consider having a statement about information sharing and confidentiality on the front page of documents about your relative, including who can update and amend
- If you notice any inaccuracies in information e.g. a letter following a hospital appointment which includes a diagnosis which does not apply to your relative, ask (in writing - a letter or email) for this to be changed

Case Study

This case study explains the benefits of having an advance statement about information sharing.

Mary lives happily with her sister Carol. For the last two weeks, Mary has become increasingly manic with hyperactivity and agitated conversations lasting well into the night. Carol finally persuades Mary that she needs professional help. By now they are both stressed, exhausted and angry. Mary tells the doctor she wants no further contact with her sister and doesn't want her involved in any discussions about her care. Fortunately, there was a note in Mary's records stating that, when she was well, she had given permission for information and decisions to be shared with her sister if she became ill again.

Read the full case study and resource

Family carers sharing information about their relative

When sharing information about your relative, think about:

- Why does this person need to know this information?
- Will my relative feel embarrassed if they know I have shared this information?
- Will it impact on how the person views my relative? e.g. if you share information about a mental health diagnosis or behaviour described as challenging
- Would I be happy if this type of information was shared about me in this situation?
- Will this information be recorded, where and for how long?

Family carers, information sharing and confidentiality

The same rules about information sharing and confidentiality apply to family carers. Health and social care professionals should not share information about you or your family without your consent.

Advocacy, information sharing and confidentiality

If an organisation has achieved the Advocacy Quality Performance Mark for confidentiality, here is what it should have in place:

- A Confidentiality Policy that reflects current legislation. It will be clear about how personal information held will be kept confidential and under what circumstances it may be shared, when a clear explanation will be recorded. Advocates must also be aware of situations that require making a safeguarding referral.
- A current Non-Instructed Advocacy Policy in place, which makes clear the organisation's approach to confidentiality and data sharing where a person is unable to consent.
- An up-to-date Data Protection Policy in place.
- The organisation complies with data protection legislation by creating, storing and disposing of electronic and manual records appropriately.
- Any accidental, negligent or wilful breaches of confidentiality are reported at the earliest opportunity to senior managers or Board members in line with the organisation's policies and procedures.
- People know that they have the right to see their own records and are supported to have access to them if they so wish.

Freedom of Information (FOI) Act

Using the Freedom of Information Act is a useful way for family carers to access information either about their relative's care and support and/or treatment or the service they are using.

Anybody has the right to submit an FOI request, and public bodies are legally required to respond to these requests within 20 days. Not all requests will be successful, however, as public bodies are able to refuse a request based on:

- Being too expensive to comply with
- If it is 'vexatious' (an inappropriate or improper request)
- If it is a repeat of a previous request

Read about the exceptions to the FOI Act

Information can also be withheld if it is exempt from the FOI Act, for instance if it might cause harm, or if it is already due for publication. A full explanation of exemptions has been published by the Information Commissioner's Office.

To improve your chances of accessing the information, it is important to:

- Submit your request in straightforward language
- Include your name, address and contact details
- State that you are requesting information under the Freedom of Information Act
- Be specific about the information you are requesting
- Try not to overload your request as this will make it more likely to be rejected - break it up into the separate parts you require, submitting separately if needed
- Make sure that the request is being sent to the right place

Most public organisations have webpages explaining how to submit an FOI request to them. There should be an online form, an email address, or postal address through which to contact them. See these examples from the NHS or CQC.

Freedom of Information Requests

1

Planning your FOI request

Will the information you are requesting be covered under the FOI Act? Which organisation holds the information that you're trying to access? Check their website for information on their FOI process (and how to submit your request)

2

Prepare your FOI request

Clearly state the information that you are requesting, including details (if appropriate) around the time, location, department etc. relevant to where this information will be recorded. Follow the points listed above to increase the chances of success

3

Submit your FOI request

Using the correct address for submission, submit your FOI request. You may get a confirmation email with a reference code. You should get a full response within 20 days of submission

4

The response to your FOI request

If successful the organisation will respond and let you know if they have the information. If your request has been approved, you should receive the information (likely as an email or email attachment)

If not successful

The organisation should provide a reason for not approving your request. They may not have this information, or it might be excluded from coverage under the FOI Act. It might be possible to resubmit your request with adaptions made in line with their reason given

Further information

For more information on the Freedom of Information Act read this resource by the Campaign for Freedom Information
https://www.cfoi.org.uk/wp-content/uploads/2013/09/foi_guide.pdf

Information on Rethink Mental Illness website
https://www.rethink.org/advice-and-information/carers-hub/confidentiality-information-and-your-loved-one-for-loved-ones-of-people-living-with-mental-illness/

The Mental Health Act Code of Practice (Chapter 4 Information for Patients, Nearest Relative, Carers and Others) gives clear guidance about the involvement of you and your relative in their care, support and/or treatment, including information sharing and confidentiality
http://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/435512/MHA_Code_of_Practice.PDF

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Whistleblowing

This section of the Family Carer Advocacy Pack covers whistleblowing. In 2011 the BBC aired a Panorama programme showing the abuse and neglect of people with a learning disability, autism or both in a service called Winterbourne View. This scandal came to light after a staff member contacted the BBC who subsequently recorded their undercover journalist's findings. The staff member felt that they had no choice but to contact an external agency because despite raising concerns and making complaints about the care and support and treatment of people with a learning disability, autism or both using internal reporting procedures, this did not result in any changes. This type of disclosure is referred to as whistleblowing. Whistleblowing is defined as the act of speaking out about wrongdoing in the workplace.

The Public Disclosure Interest Act 1988 protects whistleblowers if they report any of the following:

- A criminal offence, for example fraud
- Someone's health and safety is in danger
- Risk or actual damage to the environment
- A miscarriage of justice
- The company is breaking the law, for example does not have the right insurance
- You believe someone is covering up wrongdoing

A whistleblowing concern can be raised at any time about an incident that happened in the past, is happening now, or may happen soon.

Closed Cultures and Whistleblowing

CQC define a closed culture as "*a poor culture that can lead to harm, which can include human rights breaches such as abuse. Any service that delivers care can have a closed culture*". Closed cultures make it difficult for staff to raise concerns or make complaints so they may rely on whistleblowing instead.

Read their guidance for CQC staff: Identifying and responding to closed cultures' which includes the characteristics of closed cultures

One identified characteristic by CQC is poor and weak management and leadership, including:

- There are regular changes in management or managers are not regularly present and at times the service may run without a manager.
- Managers do not lead by example.
- Managers fail to monitor, and address issues raised by staff.
- Information about concerns or whistleblowing are covered up, e.g. falsifying records.
- Staff are not supported or encouraged to raise concerns.
- The workforce comprises members of staff who are either related or friends, causing 'cliques' (closed group) to form and shift patterns within the service mean that the same people are always working together, and staff are not mixing with other colleagues.
- Allegations of staff bullying other staff and how this is managed. There is often a link between staff bullying and poor care and support and/or treatment.
- There is a high turnover of staff, consistent staff shortages and a high use of agency staff who do not know the people they are supporting.
- There is a lack of suitable induction, training, monitoring, and supervision of staff.
- During COVID-19, employment checks were not as thorough, giving job applicants who could harm people who use services greater opportunities to be employed.

All the above can contribute to staff lacking the confidence or being worried and frightened about the consequences of raising concerns, making a complaint and whistle blowing. This may result in them reaching out to an external organisation or alternatively disclosing their concerns to you (family carer). This can be distressing for both parties but now you have this information you will have to act on it.

You should:

- Not promise to keep the information confidential, e.g. agree to take no further action
- Encourage the staff member to disclose the information personally, including:
    - As a safeguarding referral to the local authority
    - To the CQC
    - To the NHS, if this is who runs the service
- Make your own safeguarding referral and report to CQC
- Speak to the person responsible for commissioning your relative's service and ask them to investigate
- Tell the staff member about the charity PROTECT which provides free confidential advice to staff who have concerns about wrongdoing in the workplace or Speak Up Direct which is a whistleblowing helpline for staff working in the NHS or social care sector

Key message:
If the information disclosed to you leads you to believe your relative (or somebody else) is in immediate danger you must call the police.

Further information

Support relating to abuse of people with learning disabilities

When things go wrong

This section of the Family Carer Advocacy Pack covers what to do when things go wrong, starting with ideas about how to avoid this through to making a formal complaint. Providing feedback, raising a concern, or making a complaint is different from safeguarding. If the safety of your relative or anyone else is in question, or you know somebody is being abused then immediate action is required.

Individual organisations will have their own processes but in general there are 3 main stages to follow when raising a concern or making a complaint. Depending on the issue, you may need to miss a stage and go straight to making a formal complaint or a safeguarding referral.

Stage One

How to reduce the risk of needing to raise a concern or make a complaint:

- Develop a good relationship with the health and social care professionals involved in your relative's life and work in partnership
- For the professionals who are involved in your relative's day to day life, e.g. support staff, agree to have regular feedback sessions to identify what is working well and areas for improvement. Make sure that what is working well is recorded, e.g. positive behaviour support plan, communication passport. Information about what makes a good day is far more important than what causes a bad day
- Make sure assessments (e.g. Care Act) are used as a guide to what should be happening. This means that it is not you - personally - asking for something to improve, change but what has been commissioned (paid for)
- For areas that need to improve, agree what needs to happen, who needs to do it and by when. Putting this into an action plan format is a good idea

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- Keeping records means that if you do have to raise a concern or make a complaint you have evidence of what has already been done to try and resolve any issues:
    - keep copies of all written correspondence, e.g. letters and emails
    - dates and times of telephone calls, who you spoke to and a summary of what was discussed
    - details of answerphone messages including dates and times and whether you left a message or the other party left you a message. If your service allows you, save the messages
- Dealing with any issues promptly can reduce the risk of things getting worse and can result in positive outcomes, e.g. identify a training need, leading to additional support for your relative or their support staff.

What is the difference between a concern and a complaint:

- A concern is something you are worried about, which can often be resolved at the time it is raised
- A complaint is a statement about something that is wrong or that you are unhappy with which requires a formal response
- You could be concerned about something and raise it, and if you are not happy with how it has been dealt with, you may then make a complaint about that concern

Raising a concern or making a complaint on behalf of your relative can be stressful. You may worry about:

- How it will affect your relationship with the professionals who are involved in your relative's care and support and/or treatment
- Whether you will be excluded (left out) going forward, e.g. not invited to meetings
- Whether your relative will be treated differently
- How to speak and what to say
- Whether it will make a difference
- The time and energy required
- Having the confidence and necessary skills, e.g. representing your relative in meetings, writing letters

When to raise a concern or make a complaint

Here are some examples of when you might want to raise a concern or make a complaint:

- You have tried to solve the issue informally, e.g. through feedback but this has been unsuccessful
- Your relative's agreed plans are not being followed, e.g. communication passport, positive behaviour support plan
- You believe that your relative's safety, health, and wellbeing needs are not being met or that they could be met better
- There have been a series of mistakes in your relative's care and support and/or treatment
- Professionals involved in your relative's care and support and/or treatment have acted unprofessionally
- Your relative's care and support and/or treatment have taken too long to be implemented
- If your views as a family carer are continuously ignored to the disadvantage of your relative's care

Stage Two

How to raise a concern

- Depending on the type of concern, the first option may be to speak directly to the people involved in your relative's day to day care and support and/or treatment
- Consider whether anyone external to the service can help you raise the concern, e.g. social worker, the person responsible for commissioning (paying for) the service, professional independent advocate, another family member or friend
- Be clear that you are raising a concern
- If the issue has already been discussed e.g. as feedback, provide proof of this
- Follow up your concern in writing (either a letter or email)

Stage Three

Making a complaint

If trying to resolve an issue through feedback or by raising a concern has not worked, then you may have to make a complaint officially either in writing or face to face in a meeting.

Knowing what to do

- All organisations have a complaints procedure. You can ask for a copy of this, or it may be available through their website. If you need it in a different format, the organisation has a responsibility to provide this
- Ask for a named person as your point of contact and their details, e.g. direct telephone number, email
- Ask for a reference number to be allocated specifically to your complaint. Use this whenever you speak or write to the relevant person/organisation about your complaint

Don't delay

- Complain as soon as possible after the event as it is much easier to remember all the details and there may be a time limit

If you are unhappy with the reply you may have the opportunity to take your complaint to a second stage. Again do so as soon as possible and explain why you are not satisfied with the first reply

Put it in writing

- Put your complaint in writing. If you don't feel confident about doing this, ask for help from another family member, friend, or professional independent advocate
- Make sure everything you write has a date on it and ask for a reply within the timescales set out in the organisation's complaints procedure
- Give your contact details (telephone, email and address) and also your preferred method of communication, e.g. if you would like all contact to be via email, say this. This means that if the person dealing with the complaint needs more information they can contact you easily
- Keep notes/write down details of all conversations and the dates they took place. Having a specific diary for this is helpful

- Cover all the relevant points as clearly and as briefly as you can
- It may be easier to use numbered lists and headings
- If you are sending a letter by post, do this using the 'signed for' service. If you are sending a letter by email and you have a delivery and read option use this. This means you can be sure that your letter/email has been received successfully
- Send copies of any letters, documents to all the people who may be affected by the complaint, e.g. if you are complaining to an organisation about the level of support your relative is receiving, include their social worker

Be clear about what you want

- Think about what you would like to happen and what changes you want to see to make things better - and state these in your complaint
- If you want an apology, say so

Be polite

- Whether writing or speaking, try to be polite and calm
- Be assertive, not aggressive

Check it through

- Ask someone e.g. another family member, friend, or professional independent advocate to read any letters/emails you are going to send. If they can't understand it, then the person you are sending it to is likely to struggle as well

Provide evidence (proof)

- Where possible, have proof to support your complaint, for example dates and times of when things have happened, who was involved, photographs (if it is appropriate to share them and consider issues such as consent, privacy) or other evidence
- Send copies (keep any originals yourself) of any documents which support your complaint. Local libraries often have photocopiers for general use

Respond appropriately

- Read all letters and documents that are sent to you relating to your complaint. If for some reason you cannot reply by the date specified because you are unwell or away on holiday, explain this and ask for more time

Attending meetings

- If possible, always take another family member, friend or professional independent advocate to meetings as a witness
- Ask if somebody at the meeting will take responsibility for making notes and agreeing actions (things that need to be done)
- Request any information discussed during the meeting is provided in writing and given to you (either on the day, emailed or posted) for your records
- If the information provided after the meeting is not accurate, raise this and request the necessary amendments are recorded

Be patient about timescales

- It may take some time for your complaint to be considered but don't be afraid to chase politely if nothing seems to be happening to progress matters and especially if agreed timescales are missed

It’s okay to ask for help

- Organisations such as your local Citizens Advice Bureau, family carer’s centres, charities or advocacy organisations may be able to assist you

When the organisation has finished looking into your complaint they should write to you, explaining:

- What they have done
- Whether they think you were right
- What, if anything, is going to change to make things better

If you are not happy with the outcome of the complaint

- You should receive a written response to your complaint, including how it has been investigated, if it has been upheld and what, if any, action will be taken as a result. This letter should explain the next steps to take if you are unhappy with the outcome including contacting the Ombudsman.

For more information on making a complaint see the Carers UK website

What is an Ombudsman

An Ombudsman is an independent person appointed to look into complaints about organisations free of charge. You must contact the Ombudsman within 12 months of when you first complained and within 1 month if you are contacting the Local Government Ombudsman.

Below are details of the Ombudsman:

- England: Parliamentary and Health Service Ombudsman Tel: 0345 015 4033 (For complaints that have not been resolved by the NHS in England, UK government departments and some other UK public organisations)
- England: Local Government and Social Care Ombudsman – Tel: 0300 061 0614 (For any unresolved complaints against local authorities and some other organisations providing local public services)

Both organisations provide detailed information about how they can help, step by step guides to making a complaint and details of recent cases and the outcomes.

Further information

Cerebra

Accessing Public Services Toolkit (for children and young people) which includes template letters
http://cerebra.org.uk/download/accessing-public-services-toolkit/

Citizens Advice

Citizen's Advice provide detailed guidance on making health and social care complaints, including an online template letter tool to include the correct information in an NHS complaint
http://www.citizensadvice.org.uk/health/get-advice-about-health-services/

NHS complaints

Read more on how to complain to the NHS
http://www.nhs.uk/using-the-nhs/about-the-nhs/how-to-complain-to-the-nhs/

Independent Complaints Advisory Services (ICAS)

Independent Complaints Advocacy Services (ICAS) – ICAS provides support to people wishing to complain about the treatment or care they receive under the NHS. Contact your local Patient Advice and Liaison Service (PALS) for your local ICAS team.
http://www.nhs.uk/nhs-services/hospitals/what-is-pals-patient-advice-and-liaison-service/

CQC

Anybody can contact the CQC and provide feedback about their personal experience, on behalf of somebody else or as a witness. If the feedback is part of a complaint, this should be sent to the service provider first. If you are unhappy with the outcome, then contact CQC. CQC can also investigate complaints related to the detention of people under the Mental Health Act.

CQC website - http://www.cqc.org.uk/help-advice/your-stories/declare-your-care

This infographic describes CQC's Declare your Care campaign
https://www.cqc.org.uk/sites/default/files/20190219_declare-you-care_infographic.pdf

Carers UK

Carers UK has a suggested template you can use if you need to write a complaints letter
https://www.carersuk.org/media/veuffntc/cuk-complaints-letter-template-d2.pdf

Further information

NHS England

Read about NHS England’s Ask Listen Do resources which are designed to support organisations to listen, learn from and improve the experiences of children and adults who have a learning disability, autism or both and their families and carers and make it easier to give feedback, raise concerns and complaints.
http://www.england.nhs.uk/learning-disabilities/about/ask-listen-do/

There is also a booklet featuring tips
http://www.england.nhs.uk/wp-content/uploads/2018/06/Ask-Listen-Do.pdf

Disability Law Service

The Disability Law Society provide free legal advice on community care, employment, housing, and welfare benefits to people with a learning disability, autism or both and their family carers to ensure that they have access to their rights and justice.
http://dls.org.uk/

Centre for Adults Social Care - Advice, Information and Dispute Resolution (CASCAIDr)

CASCAIDr is an online specialist advice charity who are experts in the legal principles that govern how adult social services operate in England including their relationship with rights to NHS services
http://cascaidr.org.uk/

Local Government and Social Care Ombudsman

Read this statement from the Local Government and Social Care Ombudsman about complaints made relating to funding disputes
http://www.lgo.org.uk/information-centre/news/2022/oct/complaints-about-english-social-care-increasingly-due-to-funding-constraints-ombudsman?fbclid=IwAR3xsPw2qLhW2k2sgpkOoEQNia39efpbU_0p3f8aG6wrqAkZtNa9D1ZhxcU

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Safeguarding

This section of the Family Carer Advocacy Pack covers raising a safeguarding concern which is different from making a complaint. If you are in any doubt about your relative's safety, or anybody else, it is better to report it. If, after investigation, it does not meet the threshold for safeguarding it may still result in a positive outcome such as identifying an unmet need for a family carer, e.g. a need for a break from caring or within a service e.g. a training need.

We all have a duty to speak out when we feel something is not right.

NHS England's definition

> “*Safeguarding means protecting a citizen's health, wellbeing and human rights: enabling them to live free from harm, abuse and neglect. Safeguarding children, young people and adults is a collective responsibility*”

The Care Act 2014 requires that all Local Authorities must have Safeguarding Adults Boards which:

- Make enquiries, or ensure others do so, if it believes an adult is experiencing, or is at risk of, abuse or neglect
- An enquiry should establish whether any action needs to be taken to stop abuse or neglect, and if so, by whom
- Arrange, where appropriate:
    - a Safeguarding Adult Review where the adult has ‘substantial difficulty’ in being involved in the process and where there is no other appropriate adult (family carer, other family member, friend, unpaid carer) to help them or
    - an independent advocate to represent and support an adult who is the subject of a safeguarding enquiry
- Co-operate with its relevant partners in order to protect adults experiencing/or at risk of abuse or neglect

Categories of safeguarding

- Physical abuse (e.g. inappropriate or unlawful use of restraint)
- Psychological or emotional abuse (e.g. lack of meaningful activities/swearing, taunting, verbal abuse)
- Sexual abuse (e.g.unwanted looking or touching)
- Financial or material abuse (e.g. spending somebody's money inappropriately/using somebody's personal belongings without permission)
- Organisational or institutional abuse (The Department of Health and Social Care definition: Including neglect and poor care practice within an institution or specific care setting such as a hospital or care home, or in relation to care provided in one's own home. This may range from one off incidents to ongoing ill treatment. It can be through neglect or poor professional practice as a result of the structure, policies, processes and practices within an organisation.)
- Neglect and acts of omission (e.g. ignoring medical, emotional or physical care needs. No proactive intervention, e.g. daily awareness - has your relative been to the toilet, routine health checks/screening such as dentist, eye health and vision, medication review)
- Self-neglect (personal hygiene, substance misuse, hoarding)
- Disability hate (mate) crime (e.g. children throwing stones at the window/name calling/ people being persuaded to do things in return for friendship, e.g. can you deliver this for me …, let's go to the pub for lunch but you will have to pay)
- Modern slavery (people being forced to work for reduced or no wages)
- Domestic abuse (threatening physical violence/ controlling someone)

Why we need safeguarding

- Help people to access the right kind of support to reduce risk and promote wellbeing
- Prevent death or serious harm
- Coordinate effective and efficient responses
- Enable early intervention to prevent the escalation of risk
- Prevent abuse and harm that may increase the need for care and support and/or treatment
- Maintain and improve good practice, learn lessons
- Reveal patterns of abuse that were previously undetected and that could identify others at risk of abuse so action can be taken. For example, following the deaths of 3 people at a service (Cawston Park), and the subsequent enquiry, the published safeguarding adults review (SAR) led to NHS commissioning a national review to check the safety and wellbeing of all people with a learning disability, autism or both in a mental health inpatient setting

Read the Challenging Behaviour Foundation's information about safeguarding including a step by step guide to what should happen in adult safeguarding cases

Why are people with a learning disability, autism or both at risk of safeguarding concerns

- Unable to tell somebody because of communication difficulties, e.g. can't speak or sign
- Nobody is listening
- Power imbalance, e.g. support staff controlling what your relative can and can't do
- Reliance on others
- Used to/acceptance of lower standards of treatment
- Lack of understanding about what being safe is
- Fear of the consequences of telling somebody
- Not knowing who to trust
- People providing care and support justifying their actions (e.g. he has behaviour described as challenging, it is the only way to manage him – referring to use of physical intervention, e.g. holding your relative and preventing them from moving)
- Closed cultures
- Being placed in a mental health service far from home which limits external oversight, e.g. through family visits or limited community presence which means nobody sees your relative and how they are being supported

The Department for Health and Social Care guidance states

> “Safeguarding is not a substitute for:
> - providers' responsibilities to provide safe and high-quality care and support
> - commissioners regularly checking the safety and effectiveness of the services they fund
> - the Care Quality Commission (CQC) ensuring that regulated providers comply with the fundamental standards of care or by taking enforcement action
> - the core duties of the police to prevent and detect crime and protect life and property”

Safeguarding and advocacy

Self-Advocacy

If your relative has capacity and is able to participate in the process they can chose to represent themselves. Or they can ask you (family carer), other family member, or friend to support them.

Family Carer Advocacy

If there is no conflict of interest then you can support your relative through the process. If your relative is not living with you, then ask the service supporting them if and how they will inform you of any safeguarding concerns. In some circumstances you have a legal entitlement to be told:

- If your relative is detained under the Mental Health Act and you have been identified as the nearest relative
- If your relative lacks the mental capacity to participate in any safeguarding processes and you have agreed to support them
- Because it is good practice to involve you unless your relative has capacity and has stated otherwise
- If you have been appointed as a Deputy

Professional Independent Advocacy

If there is nobody available to support your relative then a Care Act Advocate will be appointed. Care Act advocacy is a statutory (legal) entitlement, including for safeguarding concerns.

Many advocates are trained in more than one type of advocacy, e.g. the Mental Capacity Act and the Care Act. It makes sense that if your relative needs an IMCA and a Care Act advocate for continuity of support the same advocate represents them. Read Carol and Julia's stories to see how Warrington Speak UP puts this into practice.

Read Carol's story

Read Julia's story

Professional independent advocates, like all of us, have a duty to report any safeguarding concerns they have. Safeguarding policies and procedures vary between organisations, e.g. some organisations will seek reassurance about safeguarding concerns, others will make an independent referral.

Case study

Mr A is 24 and has autism and a mild learning disability. He is a very friendly and sociable young man, who is prone to waving and talking to most people he comes across and sees everyone as a potential friend. However, he struggles to read the intentions of others and is easily led astray and manipulated.

He lives next door to a pub, where he knows the staff and the regulars and is able to access his most frequently visited places. He likes to walk into town to talk to people he meets out and about. On such occasions he has been repeatedly tricked into stealing items from a newsagent by a group of teenagers and has given large amounts of money away to strangers he strikes up conversations with. Due to his previous experiences, Mr A was identified during a needs assessment as being at risk of abuse and neglect and a safeguarding enquiry was triggered.

The council found that, although Mr A was not currently experiencing abuse or neglect, he remained highly vulnerable to abuse due to him being well-known in his area as someone as easy to manipulate.

To assure his safety in the future, a safeguarding plan was agreed between Mr A and a social worker. This focused on developing his social skills and understanding of relationships and boundaries. The social worker worked with Mr A to consider various support options such as having a buddy or circle of support.

The social worker put Mr A in touch with an autism social group which provided sessions on skills for staying safe. As the group was based in town, Mr A's plan also included a support worker to accompany him. After the first 5 sessions Mr A was able to attend himself but continued to meet with his support worker on a monthly basis as part of the risk management strategy set out in his safeguarding plan.

Source: Department of Health and Social Care

Read the full Care and Support Statutory Guidance

Further information

Read this information from Mencap about safeguarding adults: https://www.mencap.org.uk/advice-and-support/safeguarding/safeguarding-adults

Read Advonet's leaflet and Cloverleaf Advocacy's factsheet for more information about the Care Act and professional independent advocacy

Advonet's leaflet
https://advonet.org.uk/wp-content/uploads/2022/02/Care-Act-Advocacy-leaflet-v3.1-December-2021.pdf

Cloverleaf Advocacy's factsheet
https://cloverleaf-advocacy.co.uk/includes/items/pdf/4213_cloverleaf-factsheet-8.pdf

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Making a legal challenge

This section of the Family Carer Advocacy Pack contains information about the laws which apply to your relative's and your rights (as a family carer) e.g. the Human Rights Act, the Equality Act, and the Care Act. These laws state what public authorities and organisations should do when involved in the care and support and/or treatment of your relative and you (as their family carer). However, there is plenty of evidence that this is routinely not happening. This section explains how you can take legal action if raising a concern or making a complaint does not result in an improvement.

Involving a solicitor

If providing feedback, raising a concern, or making a complaint has been unsuccessful in bringing about change or the law is not being followed, there may be a need to involve a solicitor to ensure your relative's and your (family carer) rights are met.

Instructing a solicitor

It is likely that your relative will qualify for free legal representation, which is funded by legal aid. Any solicitor you instruct who is able to offer assistance should discuss this fully with you. Talking to a lawyer does not commit you to taking legal action.

A solicitor can only represent a person if they are instructed to do so. If your relative has been assessed as lacking the mental capacity to instruct a solicitor themselves, then a 'Litigation Friend' can do this on their behalf for a specific case. If there is no one suitable to act as Litigation Friend, the Official Solicitor (a Public Officer funded by the Government) may act as a Litigation Friend.

Having a 'Litigation Friend' enables your relative to access the justice system and the legal solutions that are available, for example a court case relating to:

- A civil case, except a tribunal
- A family case
- A Court of Protection case

Who can be appointed a Litigation Friend

There are two groups of people who can be appointed as a Litigation Friend:

1. A person who has Deputyship
2. If there is no appointed Deputy, then an appropriate adult (this could be you) can put themselves forward as a Litigation Friend, if they meet certain criteria:

- Can fairly and competently represent your relative
- Have no conflict of interest and
- Agree to pay any costs your relative may be ordered to pay in relation to the proceedings subject to any repayment they might be entitled to

Finding a suitable solicitor

Before agreeing to represent your relative or you (as a family carer) any solicitor will want to be confident that there is a strong case, e.g. they are likely to win. Legal firms that have expertise in areas of the law related to health and social care often have a high demand for their services. To help them work out whether they can take on your relative's or your case:

- Try to be clear about what issue you need legal advice about and tell the solicitor the most important things. You can provide more detailed information later, if required
- Think about what you are aiming to achieve, such as:
    - a decision to be prevented or overturned
    - justice for a situation that you believe was unlawful, or
    - to have your concerns taken seriously

Legal firms have varying areas of expertise, so you need to decide which one is the right firm for you.

Top tips for finding an appropriate solicitor

- Use the Law Society's Find a Solicitor service
- Look at the firm's website and read any examples of the kind of work they do
- Ask what similar cases they have had experience of
- Find out what their approach to the case would be

Funding legal advice

- Legal aid, which is based on income, so if the legal representation is for you (as a family carer) then your income will be assessed
- If the legal representation is for your relative and their only source of income is from benefits, they are likely to be entitled to legal aid
- For legal aid cases, solicitors must also have the necessary authority to do so in the relevant area of law
- You can contact Civil Legal Advice (on 0345 345 4345) who have a database of solicitors who work on a legal aid basis who they can transfer you to

To find out whether you are eligible for legal aid, use this government legal aid checker

Visit the Civil Legal Advice website

- Self-fund. Ask how much the solicitor's fees will be for each stage. Costs can quickly add up and if your case goes to court a barrister's time is an additional expensive cost
- A Conditional Fee Agreement can enable you to take a negligence (damages) case to court - this is often called 'no win, no fee'
- Use Legal Expenses Insurance (which may be part of your home or car insurance) or if you are a Union member, your union may cover the fees

Any solicitor who is willing to assist you should discuss funding options with you fully at the start and should not charge you for any work unless you have agreed this in advance. Many solicitors will offer to review your request for assistance free of charge.

Further Information

Charities who offer legal advice and support

Citizens Advice and Law Centres

To find out more about getting legal advice or representation you can go to the Citizens Advice website or find a local Law Centre
Citizens Advice website https://www.citizensadvice.org.uk/law-and-courts/

Law Centres Network website https://www.lawcentres.org.uk/

Disability Law Service

The Disability Law Service provides free legal advice about community care and support, employment, housing, and welfare benefits to family carers. and their relatives to ensure that they have accurate information about their rights.
Read about some of the ways in which they have supported family carers and their relatives https://dls.org.uk/our-impact/success-stories/
Watch a short video clip https://www.youtube.com/watch?v=Wk5VfQhqQME

CASCAIDr

If you need legal advice or representation specifically related to the Care Act contact CASCAIDr. CASCAIDr is an online specialist charity who provide advice and support about the legal principles that say how adult social services operate in England and link with rights to NHS services.
Visit CASCAIDr's website https://cascaidr.org.uk/

Mencap

Mencap has a range of legal toolkits covering topics such as social care, education, housing, and advocacy
Mencap website https://www.mencap.org.uk/

The Equality Advisory & Support Service

The Equality Advisory & Support Service has a helpline which offers advice about any issues relating to Equality and Human Rights and they also have a number of template letters which may be useful, e.g. a failure to make reasonable adjustments
Equality Advisory & Support Service Website
http://www.equalityadvisoryservice.com/app/answers/list

Living a Good and Meaningful Life

This section of the Family Carer Advocacy Pack is about living a good and meaningful life and the laws that protect this.

There is little argument that everybody, including people with a learning disability, autism or both, regardless of whether they have a mental health diagnosis or use behaviour described as challenging as a form of communication, is entitled to a good and meaningful life. This is protected by certain laws including the Human Rights Act, the Equality Act, and the Care Act. And yet this is still not a reality for so many people with a learning disability, autism or both despite the closure of long stay campus style provision, white papers, reform programmes following each scandal and report after report. The Assurance Transformation data for March 2023 shows there are currently 2,065 people with a learning disability, autism or both in mental health services. This represents only a 29% reduction since 2015. The target for 2020 was 35%.

> ***Life for people with major disabilities supported by good services will often look quite ordinary, but this ordinariness will be the product of a great deal of careful planning and management.***
> Mansell report, 2007

Read the CBF’s
- 8 ways to get a house
- planning your house

This visual from Helen Sanderson Associates summaries what good care and support planning looks like

This resource from United Response which explains person centred support though video clips

Read about Pathways Associates approach to person-centred planning

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Whilst there are several models of care and support which aim to promote a good and meaningful life, they all include key components:

Person-centred care and support

Person-centred care and support provides your relative choice and control over their life: where they want to live, the type of housing, how they spend their time and the staff who support them.

Communication

Ensuring your relative's care and support is person centred means they should be given the opportunity to communicate, in the way that suits them, their likes, dislikes, wishes, feelings, values and beliefs to people who understand them and listen.

Getting the right staff

Read this information from NDTi about matching staff to the people they support. There is a simple tool to fill in to help with this.

Click here to read the article

Once completed this information can be used to develop a job description and person specification for the role of caring and supporting your relative. For example, if swimming is an activity your relative enjoys and likes to do regularly, then support staff should be able to provide support and participate alongside your relative. If your relative likes to be out and about but can't use public transport but they do have their own car, then support staff should be able to drive.

Your relative and you (family carer) should be involved in the recruitment of support staff.

Visit the Skills for Care website which has information about employing and training staff (including how you can apply for funding for specialist training such as sign language). They also have templates for job descriptions, person specifications, contracts, which can be adapted to suit your relative's personal circumstances.

Click here to read the article

Positive risk taking

> ***What good is it making someone safe, if it merely makes them miserable?***
> Source: Justice Munby in 2010

Part of living a good and meaningful life should involve new experiences e.g. getting a volunteer role or paid job, trying different leisure activities, going on holiday, having a go at cooking. This is likely to involve planning and may include a risk assessment. Risk assessments should always be seen as a way of ensuring your relative can participate, not a list of all the reasons they can't, participate in an activity. We all take risks every day and whilst we may not fill out a risk assessment form, we carry out some form of checking what we need to consider.

Your relative's entitlement to reasonable adjustments under the Equality Act should ensure that they can be requested if it increases their opportunity to participate in community activities, e.g. access to a quiet area to change at the swimming pool.

Watch this video clip from SCIE about positive risk taking and quality of life.

Read this factsheet "Making it happen" from the CBF which explains how to manage risk positively. Although it was written for Covid, it still applies.

Being independent

In addition to trying new experiences, your relative should have the opportunity to develop their existing skills and independence. This relies on being surrounded by people, including support staff, who are trained and skilled in providing capable environments and understand programmes such as active support.

Capable environments

Read this paper which describes the characteristics of a capable environment

or download this infographic

Active Support

The main principle of Active Support is engagement in meaningful activity and relationships and there are four essential components:

1. Every moment has potential
2. Little and often
3. Graded assistance
4. Maximising choice and control

This resource provides more information, including case studies about how Active Support works in everyday life for people with a learning disability, autism or both

This resource explains how active support successfully works alongside positive behaviour support

Trauma Informed Care

Like everyone, there may be times when life for your relative becomes a challenge. This can be due to events which have happened in the past, in the here and now or a combination of both, e.g. historic or current abuse. Not managed well this can result in a deterioration in emotional and mental health e.g. depression, an increase in behaviour described as challenging or both. Ultimately this could lead to admission to a mental health service. Once your relative is admitted to a mental health service, discharge and returning to a good and meaningful life in the community is difficult for many reasons, including:

- Loss of skills
- Deterioration in mental health and/or an increase in behaviour described as challenging
- Lack of local presence
- Loss of relationships

The average length of stay for people with a learning disability, autism or both currently in mental health hospitals is 5.3 years. The data for March 2023 shows that there have been 220 delayed discharges. The main reasons include:

- Lack of suitable housing
- Awaiting residential home
- Lack of social care support

One way to support your relative's emotional and mental health and/or increase in behaviour described as challenging is to ensure that trauma informed care is an integrated part of their care and support.

Click here to read more

Crisis prevention and intensive support

Crisis prevention can also support your relative to lead a good and meaningful life in their community instead of admission to a mental health service. there are times when some people will need additional support. Some areas have "intensive support teams" who can provide additional support and expertise.

Evidence from family carers identifies a number of key life events which can contribute to deterioration in emotional and mental health and/or increase in behaviour described as challenging which often led to admission to a mental health service. These include:

- Poor transition planning from children to adult services. Of the 2,065 people with a learning disability and/or autistic people currently in mental health hospitals, 220 are children (Assuring Transformation data – March 2023)
- Personal or family crisis
- Placement breakdown
- Deterioration in physical health
- Puberty/adolescence
- Change of living arrangements such as leaving the family home

Visit this link to download survival guides from Bringing Us Together

Visit SCIE's webpage about prevention and wellbeing

Family carers should always challenge any suggestion that their relative is admitted to a mental health service. The Mental Health Act is very clear that care, support and/or treatment in the community should always be considered first. The professionals suggesting admission should be able to give clear evidence why this is the only option. If your relative is at risk of admission, e.g. they have previously been admitted, have a mental health diagnosis and/or behaviour described as challenging then there should be a crisis plan in place which includes proactive strategies.

Part of managing the risk associated with behaviour described as challenging is the use of functional analysis. This means acknowledging that all behaviour is a form of communication and trying to identity the message.

Visit this link from the CBF which includes information about understanding behaviour described as challenging, finding the reason and supporting change

What is the responsibility of the local authority and NHS to ensure my relative has a good and meaningful life:

- Your relative is entitled to a robust transition plan to ensure a successful move from children to adult services.
- A Care Act assessment will identify your relative's needs and entitlement to care and support to ensure their wellbeing. As a family carer you are also entitled to an assessment to ensure that you can continue in your role for as long as you want too
- Integrated Care Boards (ICBs) are required to develop and maintain registers to identify people with a learning disability, autism or both who are at risk of admission to mental health services because of their mental health, or behaviour described as challenging or both and ensure that they have community services available to provide the necessary support.

The Care Act and Wellbeing

'Wellbeing' includes:

- Personal dignity including treating your relative with respect
- Physical and emotional and mental health
- Protection from abuse and neglect
- Control by your relative over their day-to-day life including over care (e.g. limiting independence) and support provided and the way they are provided
- Participation in education, training, work or recreation
- Social and economic wellbeing
- Domestic, family and personal circumstances
- Suitability of your relative's living accommodation
- Contribution to society

This CQC report Home for Good celebrates successful community support. It includes 8 stories of people with a learning disability, autism or both who have previously been admitted to mental health services. All are now thriving in community services across England. There is no single model of care and support that explains this success. Each story is different. However, common threads emerge:

- **Services must be bespoke and truly person-centred.** This entails understanding and acting on what a person wants and needs. This includes recruiting and training specialist staff teams.
- **Agencies should work in partnership.** In particular, service providers should co-operate with clinical and health professionals and community teams e.g. occupational and speech and language therapists. This must happen during service planning and once a service commences.
- **Appropriate housing and environments are essential.** This might mean specially building property or considerable adaption of an existing property.
- **When people are labelled as having challenging behaviour which includes self-harm and physical or verbal aggression, this should be understood as communication of distress or need.** This understanding often comes from the use of a Positive Behaviour Support approach.

Family involvement in all aspects of service planning and delivery increases the chance of a good outcome.

Family Carer Advocacy
As a family carer you have an important role to play in ensuring your relative has a good and meaningful life. You can share your unique knowledge about your relative: their likes, dislikes, wishes, feelings, values and beliefs and how they communicate these. You can provide information about care and support and/or treatment for your relative which has been either successful or unsuccessful and any trauma your relative has experienced. You are entitled to be involved in your relative's life and there are laws which protect your right to do this, e.g. Human Rights, Care, Mental Health and Mental Capacity Act.

Professional Independent Advocacy
If your relative does not have anybody to advocate on their behalf and they need this support, they may have a statutory entitlement to a professional independent advocate, e.g. Care Act processes, when detained under the Mental Health Act, or if decisions are being made with or on their behalf under the Mental Capacity Act. Some advocacy organisations also provide additional professional independent advocacy services, e.g. peer advocacy. This is usually dependent on funding.

Further information

Every month the NHS publishes data summarising the current admissions to mental health services. It includes a breakdown of the data e.g. by age, length of stay, reasons for delay in discharge: http://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics/at-march-2023-mhsds-january-2023-final/datasets---at

The BASW is a professional organisation for social work and social workers. Visit their website for details of key documents to support social workers to work preventatively to support, advocate and challenge on behalf of people with a learning disability, autism or both who are currently in assessment and treatment units or restrictive settings to enable a return to home as soon as possible: http://www.basw.co.uk/homes-not-hospitals

Read the Learning Disability Professional Senate Rights and Equality Based Outcomes for Learning Disability Services, including 'I' statements and case studies explaining how the Human Rights and Equality Act can be used to influence an ordinary life: http://www.bild.org.uk/wp-content/uploads/2020/01/LD-Professional-Senate-Outcomes-final-paper-September-2016.pdf

Read this service model guidance for commissioners about supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition:
http://www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdf

This guide from the Challenging Behaviour Foundation guide outlines "What does good support look like for adults with learning disabilities who display challenging behaviour":
http://www.challengingbehaviour.org.uk/wp-content/uploads/2021/02/2-What-does-good-support-look-like-for-adults-with-learning-disabilities-who-display-challenging-behaviour.pdf

This guide is part of the Meeting the Challenge series which includes:
- Understanding challenging behaviour
- Difficulties in supporting a family member
- My family member has been sent to an inpatient unit
- Concerns about poor care or abuse
- Planning a successful discharge
- Transitioning to adulthood

You can download the other guides here: http://www.mencap.org.uk/advice-and-support/wellbeing/displaying-challenging-behaviour/meeting-challenge-guides-families

Read this guide: Getting the Best Support Package – 10 top tips from the Challenging Behaviour Foundation:
http://www.challengingbehaviour.org.uk/wp-content/uploads/2021/02/16-Getting-the-best-support-package-Ten-Top-Tips.pdf

Watch the trailer for the Challenging Behaviour Foundation's Everybody Matters video about Shaun and Colleen who have experienced poor support, restrictive practices and felt unhappy and sometimes unsafe in the past. Their stories show that with the right care and support everyone can live an ordinary life in their community. If you are a family carer you can contact the CBF for a copy of the DVD:
http://www.challengingbehaviour.org.uk/information-and-guidance/when-things-go-wrong/everybody-matters/

The Challenging Behaviour Foundation has produced a pamphlet for professionals who commission services for adults with severe learning disabilities who display challenging behaviour:
http://www.challengingbehaviour.org.uk/wp-content/uploads/2021/03/Pamphlet-for-Commissioners_Adult-1.pdf

Read how the CQC has incorporated a quality-of-life tool into their inspection process for services for people with a learning disability, autism or both:
http://www.cqc.org.uk/guidance-providers/autistic-people-learning-disability/quality-life-tool

Download the PERMA Model booklet here:
http://www.bild.org.uk/resource/perma-booklet/

PERMA stands for:

- **P**ositive Emotion
- **E**ngagement
- **R**elationships
- **M**eaning
- **A**chievement

and is one way of checking that your relative has all the core elements required to lead a good and meaningful life that is person centred. For example, Engagement celebrates the things your relative can do independently to make themselves feel happy, which might include listening to the same song, or watching something spin.

Ask whether your relative can be included in the Dynamic Support Register. This means that the relevant professionals will be aware of your relative's increased risk of being detained (sectioned) without the right care and support or early intervention (e.g. community intensive support team) at times when they are in crisis https://www.england.nhs.uk/long-read/dynamic-support-register-and-care-education-and-treatment-review-policy-and-guide-plain-english-version/

All our information sheets are available to download free of charge because we believe that money should not be a barrier to getting the information you need when you need it.

Please see the end of this information sheet for details of how to support us.

We want to make sure our resources are helpful. Please spend a few minutes giving us some feedback: [Feedback form]

Communication

This section of the Family Carer Advocacy Pack covers your relative's right to communicate, different types of communication, and the importance of ensuring your relative's communication needs are successfully met.

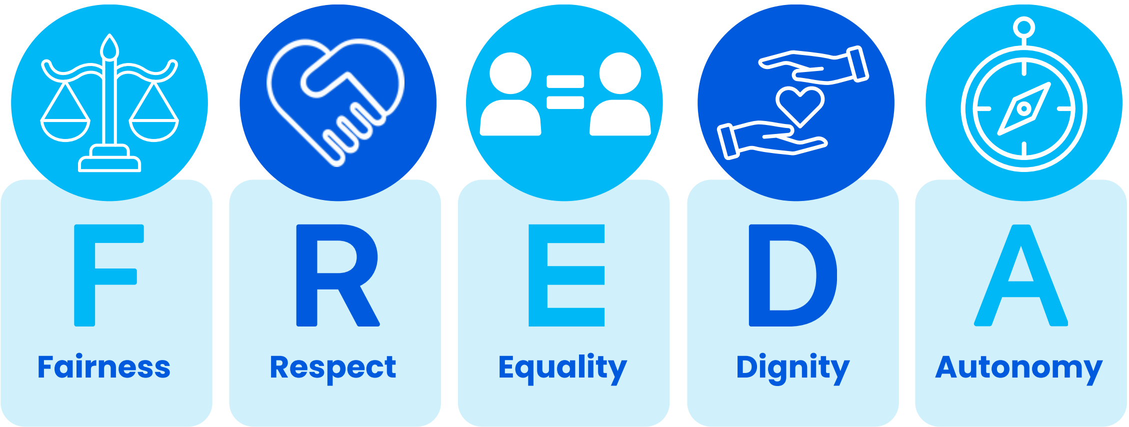
Human rights and communication

Ensuring your relative's communication needs are met is a fundamental human right. It is included in UK legislation via Article 10 of the European Convention on Human Rights and the Human Rights Act 1998. Article 21 of the 2006 UN Convention on the Rights of Persons with Disabilities confirms

> ***the freedom to seek, receive, and impart information and ideas on an equal basis with others and through all forms of communication of their choice.***

This right confirms that all forms of communication are equally important, whether it is verbal, sign, pictures/symbols, through the use technology or a combination of more than one.

Additionally, for the FREDA principles (a human rights approach) to be followed your relative needs to be able to communicate their views about their likes, dislikes, wishes, feelings, values and beliefs.



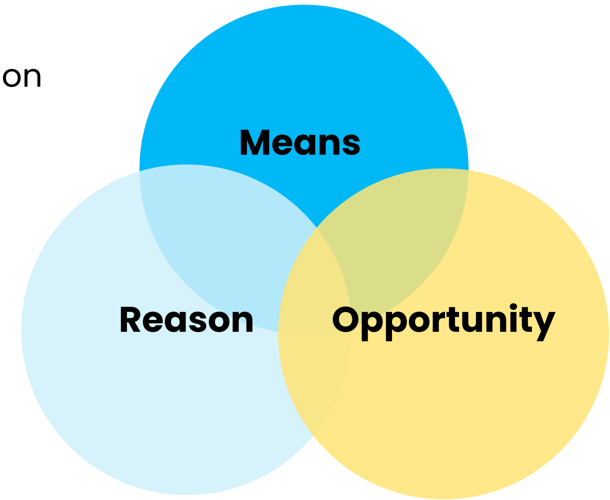
This means that the services and staff supporting your relative should have the skills necessary to communicate with your relative. This applies to both expressive (communicating with your relative and vice versa) and receptive (understanding/ listening to your relative and vice versa). If not, it is a breach of your relative's human rights.

> ***Everyone should uphold others' right to communicate as they interact with people in daily life in order to enhance equality, justice and human dignity. "***
> Sharynne McLeod, Professor of Speech and Language

What is communication

There are three key parts that make communication effective:

- Means (how)
- Reason (why) and
- Opportunity (when)



The opportunity:
People can only communicate with others when they have frequent chances. People with a learning disability, autism or both do not always have the opportunity to communicate, e.g. if they use sign language but nobody else around them does. Limited opportunities can affect the learning and development of communication, other skills and impact on mental health.

The reason:
Refers to why communication takes place, for example:

- expression of practical needs, e.g. asking for a drink, communicating pain
- expression of thoughts, opinions and feelings e.g. I'm feeling sad, happy, angry, bored
- sociable e.g. to ask someone their name, to make friends

The means:
Refers to how a message is sent. This may occur via spoken or written words, sign language, body language, gesture, assistive communication devices or any other means the person uses. People need to be able to use the means of communication that best suits their needs

A study carried out by the School for Social Care Research found the following:

Click here to read the study

Support staff think people understand more than they do.

What does this mean for your relative – communication is not pitched at the right level. Staff may think they have asked your relative to do something, told them what is happening but your relative has not understood this.

Staff did not appear to see communication and spending time with people sociably as part of their role.

What does this mean for your relative – they may spend time feeling ignored and lonely, whilst support staff participate in administrative or household tasks.

Adapted methods of communication were rarely seen.

What does this mean for your relative – if their expressive and receptive communication is not via fluent speech they will spend a lot of time not knowing what is happening or enjoying the social aspect of communication.

Information from family carers about their relative's communication/interaction did not seem to be valued.

What does this mean for your relative – the expertise and knowledge you have is not being used to ensure that your relative's communication environment meets their needs.

Communication support did not appear to be targeted at those who experience the greatest communication challenges.

What does this mean for your relative – the greater your relative's communication needs the less time and effort is being invested in communicating with them.

Without the appropriate communication support people with a learning disability, autism or both may be at risk of:

- A lack of choices and involvement in everyday decisions
- Limited relationships and isolation
  More likely to be abused
- Poor mental health, including low mood, anxiety and depression
- Not joining in community life
- Less employment opportunities
- Lower standard of healthcare, risk of diagnostic overshadowing, and more inpatient admissions, e.g. assessment and treatment unit
- Support staff restricting activities because of behaviour described as challenging because this is not acknowledged as communicating an

- Support staff restricting activities because of behaviour described as challenging because this is not acknowledged as communicating anunmet need. This could lead to people losing where they live and their support package.
- Increased risk of not following rules or breaking the law

  Limited access to therapies or programmes which rely on verbal communication, e.g. prison/hospital rehabilitation programmes which can contribute to delays in discharge

Without the appropriate communication support people with a learning disability, autism or both may be at risk of:

- Up to 90% of people with learning disabilities have communication difficulties. Around half have significant difficulties with both expressing themselves and understanding what others say.
- Only 5 -10% of people with learning disabilities have recognised literacy skills (reading and writing) and most are not able to access standard written information.
- The incidence of additional sensory impairments, including sight and hearing, is much greater than in the general population. Up to 40% of people with learning disabilities, autism or both have a hearing loss that is often missed.
- Autistic people have lifelong difficulties with social communication, social interaction and social imagination.
- As communication difficulties increase, behaviours described as challenging typically increase in frequency (how often), intensity (how challenging) or duration (how long).
- Having a communication difficulty means people with a learning disability, autism or both are misunderstood, experience failure and exclusion from events, activities and relationships.
- Physical difficulties, e.g. dyspraxia can make the production of speech challenging.
- Developing communication over a person’s lifespan is not seen as a priority, e.g. increasing vocabulary in line with new experiences.

Person-centred communication support reduces these risks. It enables:

- **Inclusive relationships**
- **Choice and control**
- **Greater independence**
- **Improved health outcomes**
- **Improved quality of life**

Good communication standards

The Royal College of Speech and Language Therapists has identified five recommended 'Good Communication Standards' for providers of specialist hospital and residential services. These standards provide a framework which family carers, other family members, friends, professionals and commissioners can use to judge whether a service is providing the right communication environment for your relative.

The five good communication standards:

Standard 1: There is a detailed description of how best to communicate with individuals.

Standard 2: Services demonstrate how they support individuals with communication needs to be involved with decisions about their care and their services.

Standard 3: Staff value and use competently the best approaches to communication with each individual they support.

Standard 4: Services create opportunities, relationships and environments that make individuals want to communicate.

Standard 5: Individuals are supported to understand and express their needs in relation to their health and wellbeing. Everyone has the ability to communicate even if they do not have the ability to speak – communication does not just include the spoken word.

Read the full report here

No words but lots to say

Find out more about the CBF's Seldom Heard Project

> ***My daughter was a woman without words, but that did not mean she had nothing to say! This was true when she was very young, right throughout her life, including about her end-of-life care.***
> Jean Willson, Family Carer (Seldom Heard Project)

Total communication

A Total Communication approach uses additional ways as an alternative or to support spoken and written communication. Some examples include:

- Gestures (pointing)
- Facial expression (smiling)
- Body language (turning towards somebody)
- Signing (British Sign Language, Makaton)
- Symbols (Picture Exchange Communication System – PECS)
- Photographs
- Objects of reference (swimming costume to indicate it's time for swimming)
- Sensory objects of reference (different smells associated with different days of the week, different sounds associated with different activities)
- Augmentative and alternative communication
- Communication book (low tech book with pictures/photographs of preferred activities, topics to communicate about, important people, hobbies, favourite good)

- Chat/Talk About Book (as above but also includes things that have happened or are going to happen)
- Music therapy
- Social stories
- Intensive Interaction
- Visual supports
- Talking mats
- Books beyond words

How to support communication for people with a learning disability, autism or both

- Abstract concepts such as negatives and time might be difficult to understand. For example instead of saying "don't sit on the bed, say "sit on the chair". Using visual cues can help with yesterday/today/tomorrow e.g. a calendar with photographs
- Use short sentences, simple language and avoid jargon
- Break information into smaller chunks so that one idea or concept is explained at a time.
- Allow sufficient processing time to make sure that the person has understood
- A person's speech may sometimes give an impression of better comprehension than is actually the case, so check their understanding
- Consider a person's sensory preferences. Watch this video clip to experience what sensory overload feels like and how difficult communication must be, e.g. you can only hear the dripping tap not the voice of somebody trying to tell you something
- It can help if you can offer a visual aid such as a photo or drawing to support understanding
- If you are trying to identify like/don't like or explain advantages and disadvantages, the use of a tool such as talking mats can be effective
- Don't exclude people from conversations when discussing topics such as staffing, activities. It may result in somebody misunderstanding what is being said e.g. swimming is cancelled tomorrow, but the person may have just heard the word swimming and think it is happening immediately. In both cases this could lead to behaviour described as challenging.

Communication: speaking to people with a learning disability by Mencap

Watch Carol, Stuart and Ian – MENCAP volunteers – explain what they think makes good communication

Communication Passport

It is important to recognise and record your relative's individual style of communication. This includes if they are bilingual, or English is their second language This can be done using a communication passport. For it to be useful it must be kept up to date and easily accessible, e.g. not put in the back of a drawer in an office. It is also helpful to have a one-page portable communication passport (sometimes referred to as an 'All about me' profile) that your relative can always have with them. Include your relative in the development of their communication passport as much as possible.

Even if your relative can communicate verbally and has literacy skills (reading and writing) it might still be useful to have a one-page portable communication passport. This can include information such as:

- I communicate best in small groups
- Just because I am not making eye contact it does not mean I cannot hear you
- I don't like it if people start up separate conversations. I think they are talking about me
- When I say, "Time's up", it means I have had enough. Please do not try to persuade me to stay. It will make me distressed

Make sure that your relative's communication needs are regularly assessed to ensure that any changes are addressed. For example, if your relative stops responding to their name or loses interest in listening to music, this could indicate a change in their hearing, requiring a hearing assessment. Regular assessments will also identify any gaps in skills and training for staff and for your relative e.g. vocabulary teaching for emotions, introduction of additional communication systems such as PECS or sign language. After an assessment make sure that your relative's communication passport is updated, as required.

If your relative does not already have a communication passport here are some suggested templates:

Click here for a range of templates

Click here for a template from Include Me TOO

Use this template from Change which can be folded down to make it pocket size

Read about Laura's communication passport on the CBF website

Behaviour described as challenging and communication

Your relative may display behaviour described as challenging as a way of communicating an unmet need or to control their environment, particularly if experience tells them it is effective. For example, if your relative learns that every time they are left alone, if they throw something a member of staff comes and sits with them, they may continue this behaviour as a way of gaining social interaction. Over time they may generalise this behaviour as a way to get their needs met or adapt their environment.

If you think that your relative is displaying behaviour described as challenging as a form of communication, ask for a functional assessment to be carried out. A functional assessment looks at the message behind the behaviour. The findings from the assessment should be recorded in a behaviour support plan and specify any changes which need to occur, e.g. instead of waiting until your relative throws something to gain social interaction, provide this regularly and also teach your relative how to ask for some company, e.g. sign "chat", or tap somebody.

Visit this link from the Challenging Behaviour Foundation about finding the reasons for behaviour described as challenging

Read what the NICE guidelines say should happen as part of a functional assessment

> ***Imagine that you have a very limited understanding of speech, and you are unable to express your feelings. The people around you don't understand you. Imagine that you keep trying to communicate in your own way, but they just keep on speaking to you. You don't make a fuss, so they sit you in a chair in the lounge all day, every day and they think you are happy to sit there because you don't make a fuss. Imagine that you try a different way of communicating and then they say you are too challenging to take out. So now you sit in your chair in the lounge all day, every day.***
>
> Total Communication Film 2009

Advocacy and communication

If your relative has good communication skills, regardless of the method, they may be able to independently tell people involved in their life what they like, don't like, what they want, their feelings, wishes and aspirations. This is called self advocacy. On occasion though, like all of us, your relative may need additional support, e.g. to make telephone calls, attend meetings. They can access this informally through you (family carer), another family member, a friend, or contact an advocacy organisation to ask for help.

Here are some Advonet resources to support self-advocates

Some people with a learning disability, autism or both may use other methods to make choices, e.g. signing, pushing their plate away if they don't like a meal, kicking off a particular pair of trainers. This is still communication and should be listened to carefully and recorded in a communication passport, e.g. If Ben pushes his plate away he is saying ….. I don't like the meal, I am not hungry, I don't feel well. If it is a meal he usually eats consider the second two options but also does the meal look/taste like it usually does, is there something happening in the environment, e.g. noise and lighting levels.

If a more complex decision is required, your relative may need somebody to advocate on their behalf. Again this could be you (family carer), another family member, friend or a professional independent advocate. Any decision should be in your relative's best interests, and this is called non instructed advocacy.

Watch this video clip about how a decision is made when a young man is moving home. It combines listening carefully and using background information from somebody who knows him well

The Accessible Information Standard (AIS)

The Accessible Information Standard (AIS) was introduced by the government in 2016. It is now the law for all NHS and adult social care services (e.g. doctors, dentists, hospitals, social workers) to comply with the AIS. If you have a learning disability, autism or both NHS or adult social care services need to:

- Find out your relative's communication and information needs.
- Record these communication and information needs clearly and consistently.
- Flag these needs, so when a member of staff opens your relative's record it is clear what their communication needs are.
- Share your relative's communication needs for example if they are referring to another service.
- Take action to give your relative the right support. For example, arranging for somebody who can sign, offering easy read information, providing information in a visual format, allowing somebody to accompany your relative to support their communication.

Need help with communication?

Here's **five things NHS and social care services MUST do** if you need help to understand information about your treatment or care (e.g. if you need an interpreter).

Check — You should be asked about your needs.

Record — Your preferences for communication should be recorded in your notes.

Visibility — Your needs should be flagged to staff when they communicate with you.

Share — If you are referred, your needs should be shared with other services.

Meet Needs — Your needs must be met. The service should be communicating about your care, your way.

If your needs are not being met... Let the service know! You have a right to receive information in a way you can understand it. If that's not happening, you should contact the service and ask them to address it.

You can also feedback to Healthwatch Suffolk on www.healthwatchsuffolk.co.uk, or call freephone 0800 448 8234.

healthwatch Suffolk

Five things NHS and social care services MUST do by Healthwatch Suffolk

Accessible Information Standard by NHS England

Visit the National Autistic Society's website here for more information about communication

Physical, Emotional and Mental Health

This section of the Family Carer Advocacy Pack is about your relative's right to be healthy. Having a physical health condition significantly increases the risk of developing an emotional and mental health condition and vice versa.

Nearly one in three people with a long-term physical health condition also have an emotional and mental health condition. If your relative is in pain (either chronic or acute) and this is not addressed, it can impact on mood and could lead to depression or an increase in behaviour described as challenging.

The Learning from the Lives and Deaths of People with a Learning Disability and Autistic People (LeDeR) Programme

In 2017 the LeDeR programme was established. It aims to:

- Improve care
- Reduce health inequalities
- Prevent the early deaths

of people with a learning disability, autism or both.

The LeDeR publishes an annual report and every year it confirms that people with a learning disability, autism or both face many health inequalities, often resulting in worse health than the general population: Here is some of the information from this year's reports:

Useful terms:
Chronic or persistent pain is pain that carries on for longer than 12 weeks despite medication or treatment. Acute pain begins suddenly and is usually sharp. It serves as a warning of disease or a threat to the body. Examples of acute pain include a broken bone or cut.

- 62 was the average age of death for people with a learning disability, autism or both. In the general population it was 82.7
- 49% of deaths were classified as 'avoidable' for people with a

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- Learning disability, autism or both. This compares to 22% for the general population
- COVID-19 was the leading cause of death for people with a learning disability, autism or both in 2021
- 8% of avoidable deaths were linked to cancer, 14% to hypertension, 17% to diabetes and 17% to respiratory conditions

See the full summary factsheet or read the most recent report:

Click here to look at the full summary factsheet

Click here to read the most recent report

Article 2 of the Human Rights Act protects your right to life. This right places an obligation on public authorities to provide life-saving or life-prolonging medical treatment. If a health and social care organisation or professional knowingly withhold care and support and/or treatment this can be classed in law as ill treatment/wilful neglect.

Emotional and Mental Health

People with learning disabilities, autism or both are just as likely to experience poor emotional and/or mental health, with some research indicating there is an increased risk. Despite this, mental health conditions in people with a learning disability, autism or both often go undiagnosed.

Mental health includes emotional, psychological, and social well-being. It affects how people:

- Think
- Feel
- Act and behave

Key Message

Learning disability and autism are not mental health conditions. The Mental Health Act reforms include removing the terms ‘learning disability and autism’ from the list of conditions included under the definition of ‘mental health disorders’. This means that it will be harder to detain people with a learning disability, autism or both under the Mental Health Act unless there is a clear mental health diagnosis, e.g. depression, psychosis. In addition, all current guidance emphasises the need for any interventions for a mental health condition to be available as early as possible and in the community because it is acknowledged that the outcomes for people with a learning disability, autism or both are rarely positive following admission to a mental health service.

Read this fact sheet ‘What’s the difference between a learning disability and a mental health problem?’ from Mencap

There are a number of reasons why your relative has an increased risk of developing either a physical or emotional and mental health condition or both. Here are some examples:

	Physical Health Conditions	**Emotional and Mental Health**
Biological factors		
Some syndromes and diagnosis are associated with an increased risk of developing certain physical and/or emotional and mental health conditions	Down's Syndrome and heart or lung problems	Fragile X Syndrome and anxiety Prader Willi and obsessive-compulsive disorder Autism and eating disorder Response to sensory environment, e.g. being overwhelmed or finding certain stimuli such as noise, bright lights stressful
Side effects of medication	Psychotropic medication can cause: • constipation • weight gain leading to diabetes	Psychotropic medication can cause: • sleep problems (sedation or wakefulness) • overly controlled emotions both positive and negative e.g. inability to cry
Genetics	Increased risk of health conditions such as cancer e.g. being a carrier of the BRCA (breast cancer) or HNPCC (bowel cancer) gene	Increased risk due to genetics, e.g. a family history of depression. Click here to read more from Rethink Mental Illness
Social and economic factors		
Poor or inadequate housing	Overcrowding increasing risk of illnesses such as sickness and diahorrea, flu, Covid Poorly maintained housing leading to conditions such as damp increases the risk of some illnesses, e.g. respiratory	No choice about living companions which means your relative may find themselves in a position where they are living with people they don't get on with, are frightened off, have different support needs which can contribute to anxiety and/or depression

Low income, poverty	Food choices due to limited income contributing to weight management (under and over) Not enough physical activity leading to decreased mobility, weight gain because of limited income to cover for example entry fees to swimming or gym sessions	Lack of access to meaningful activities leading to poor quality of life
Negative life events		Abuse and/or trauma (including undetected) Poor transition planning from children to adult services Grief and loss: • death of loved ones • placement breakdowns • moving services • high turnover of support staff • loss of important relationships because of placements far from home
Use of restrictive interventions	Injuries due to physical intervention Blanket restrictions/risk aversion support prevent participation in physical activities	Trauma: • fear of when the next restraint/ seclusion will happen • psychological trauma such as name calling, being belittled, made to feel worthless • secondary trauma, e.g. observing a peer being restrained • poor quality of life due to blanket restrictions

Attitude of others	Healthcare professionals making assumptions about physical health needs e.g. not recognising, or not considering it important	Discrimination Disability hate crime Being treated differently
		Discouraged from using person-centred coping strategies, e.g. repetitive activities such as rocking, listening to the same song
Care and support		
Inadequate level of care and support	Prevents participation in meaningful activities including physical activity Limited person centred support and therefore choice and control	Lack of choice and control results in negative emotions like hopelessness
Quality of staff, e.g. training	Direct support staff do not have the knowledge or skills to support your relative to develop: • good daily living routines, e.g. oral hygiene, cutting finger/toe nails. Unattended this can lead to infection. • a healthy lifestyle e.g. diet and exercise No attention given to the importance of regular screening for breast cancer, testicular cancer	Emotional and mental health not prioritised or considered important by staff Staff not skilled in monitoring and detecting early warning signs of deteriorating emotional/mental health needs Staff may not be aware of their own emotional and mental health needs and how this may impact on the way they carry out their role

	Physical symptoms of stress e.g. high blood pressure	Masking. This term describes how people with a learning disability, autism or both learn (consciously or unconsciously) to try and fit in. It can be exhausting and contribute to increased emotional overload, including stress and behaviour described as challenging
		Poor self-esteem and confidence due to: • lack of opportunities for paid or voluntary work • support staff may not understand the importance of promoting independence, adopting a 'do for' or 'do too' model of care and support instead of supporting your relative to develop the skills to do things for themselves, e.g. cooking a meal of their choice No attention given to teaching coping strategies or no acknowledgement of the importance of ensuring access to activities that your relative uses to manage their mood, e.g. going for a walk, drive.

Reasons why your relative's physical, emotional and mental health may go unnoticed or untreated

- Diagnostic overshadowing. This is defined by the General Medical Council (GMC) as "symptoms of physical ill health that are mistakenly attributed to either a mental health/ behavioural problem or as being inherent in the person's learning disabilities". This means that health and social care professionals assume that any changes in your relative's behaviour are related to their learning disability, autism or both and fail to consider that their symptoms may be because of a physical, emotional or mental health condition or a combination of both.
- Communication difficulties:
    - your relative may not have the skills or have been taught the necessary vocabulary to tell somebody when they are unwell
    - if nobody is listening or checking in with your relative to ask how they are, their health needs may go unnoticed.

[This resource provides ideas about talking about feelings](#)

- Your relative may not know what is normal and what needs medical advice or intervention. For example, if your relative does not know it is important for them to go to the toilet regularly, they may become constipated. If your relative is female and their menstruation cycle stops, they may not be aware that this could be an indication of the menopause
- Making assumptions, for example your relative starts to sleep more and it is judged as laziness, instead of considering other possible reasons such as pain or depression
- Mental health conditions may develop and present in different ways compared to people without a learning disability, autism or both. For example, if your relative has good communication skills, they may be able to say that they are hearing voices, having persistent thoughts, or thinking about harming themself but if your relative has complex communication difficulties they may not have the vocabulary or skills to communicate this, except through their behaviour
- Difficulty in diagnosing using standard tools e.g. questionnaires which either require your relative to self-report or rely on other people to complete on their behalf
- Healthcare professionals lack the training or skills necessary to address and treat physical, emotional and mental health conditions, e.g. no knowledge of reasonable adjustments, medical conditions associated with specific syndromes, reluctance to treat people with a learning disability, autism or both if they are considered to have behaviour described as challenging
- Limited focus on early intervention including standard health screening

such as mammogram, smear test, colonoscopy (bowel cancer screening)

Knowing when something is wrong

As a family carer you know your relative and what is normal for them when they are well (physical, emotional and mental health) and the signs to look out for when they are unwell or in pain. Use standard tools to regularly assess your relative's health and record the findings so that any changes are noticed and addressed promptly.

Physical health

Disability Distress Assessment Tool DisDAT

Read this resource from Public Health England 'How social care staff can recognise and manage pain in people with learning disabilities':

Emotional and mental health

Guidance from NICE (the National Institute of Care Excellence) recommends that those caring and supporting people with a learning disability, autism or both should consider a mental health condition if the following changes in behaviour are noted:

- Loss of skills or needing more prompting to use skills
- Social withdrawal
- Irritability
- Avoidance
- Agitation
- Loss of interest in activities they usually enjoy

Read the full guidance here

Other changes to note include:

- Sleeping too much or too little
- Change in appetite (increase or decrease)
- Having low or no energy
- Increase or decrease in emotions, including mood swings
- Unexplained aches and pains
- "Self-medicating" through substance misuse (drugs and alcohol)
- Refusing to participate in activities they usually enjoy
- Increase in behaviour described as challenging, particularly self-injurious behaviour.

In this video clip family carers explain how their relative displays behaviour described as challenging to express pain. There is also a fact sheet you can read

You can use the Glasgow Depression Scale to monitor mood

Use this wellbeing journal to start a conversation with your relative about emotional and mental health

NICE guidelines (para 1.8) suggest a mental health care plan

Use a hospital passport to record information about your relative's health. There are many templates available, and it doesn't matter which one you use as long as the information is recorded, kept up to date and people know where to find it. Template from the National Autistic Society

Case Study

Family carer Kate tells us how her daughter Laura's hospital passport provides vital information whenever she needs any type of medical intervention in hospital: Read more here

Supporting your relative to stay healthy

- Check with your GP whether your relative is on the learning disability register
  Being on the learning disability register should ensure that your relative receives an annual health check. This is an entitlement for people with learning disabilities aged 14 and over. Since April 2008 there has been extra money for GPs who do these.
- Even if your relative sees their GP regularly an annual health check is still a good idea as it will check things that are not looked at during a regular appointment. The health check typically includes:
  - a physical check-up, including weight, heart rate and blood pressure
  - a urine sample
  - a blood test
  - a chat about lifestyle e.g. level of exercise, weight management and any support required to stay healthy
  - discussion about emotional and mental health including any changes in behaviour, e.g. being sad and crying more, lack of motivation to participate in favourite activities, getting angry easily
  - questions about health care needs that are more common if you have a learning disability, autism or both e.g. epilepsy, constipation
  - a review of any prescribed medication, including psychotropic medication
  - check to see if vaccinations are up to date e.g. Covid, flu
  - follow up on any other health appointments

Click here to access the medication pathway

Everyone who has an annual health check-up should be offered a health action plan. This could include referrals to other health care professionals such as a dietician because of concerns about your relative being over/under weight. Here are some examples of health action plan templates:

Click here to go to the learning disability page on the Surrey County Council Website

Click here for a template from Leeds North Clinical Commissioning Group

- Ask your GP if they can add information to your relative's Summary Care Record (SCR). A SCR is an electronic record of important patient information (e.g. prescribed medications, allergies, communication needs, any reasonable adjustments required) created from GP medical records which can be shared with authorised health care professionals.

Read this easy read photo story about adding additional information to your summary care record

- Find out whether the reasonable adjustment flag is operating in your local authority
- Ask for a referral to a community learning disability nurse and/or a learning disability liaison nurse
- Seek professional support for any behaviours described as challenging which could be because of an unmet health need
- Make sure you are aware of potential side-effects of any medications your relative is prescribed (including psychotropic), monitor carefully and request regular reviews.

Click here to find out more about the reasonable adjustment flag
Click here to watch a video

Click here to read more about learning disability nurses

Click here to read more from the Challenging Behaviour Foundation

Click here to read more information on the use of medication

- Input from your local Community Team Learning Disability can support your relative's physical, emotional and mental health. The referral process varies across local authorities, but most allow self-referrals. The CTLD team typically includes the following health care professionals:
    - Psychology
    - Psychiatry
    - Occupational therapy
    - Physiotherapy
    - Speech and language therapy
    - Behavioural support
    - Specialist community nursing

  and they should adopt a multi-disciplinary approach (work in partnership)
- If your relative is detained (sectioned) under the Mental Health Act, on admission your relative, or you on their behalf, should request a physical health check. This will ensure that if there are any underlying physical health conditions which are contributing to a deterioration in emotional and mental health and/or increase in behaviour described as challenging this can be addressed promptly. If during their detention, your relative develops any physical health conditions, then it is the responsibility of the service to ensure that they receive prompt and appropriate treatment

Oral health

Ensuring your relative is fit and healthy includes their oral health. A Public Health England report in 2019 looking at oral health inequalities said approximately one in three adults with a learning disability, autism or both have:

- Unhealthy teeth
- Higher rates of untreated decay
- A greater number of extractions
- A higher prevalence of complete tooth loss

than the general population.

Read this factsheet on accessing dental care

Visit this website for advice and guidance for autistic people and their family carers

Emotional and mental health

One of the best interventions to support your relative's emotional and mental health is to ensure they have a good quality of life and there is legislation in place which acknowledges this:

- Care Act and the principles of wellbeing
- Human Rights Act, e.g. article 3 Freedom from torture and inhuman or degrading treatment
- CQC's inspection process and good practice guidance

This report provides a service model for commissioners of health and social care services.

It includes a visual on page 12 illustrating the nine elements which contribute to a good quality of life

Treatment and therapies available to support your relative's emotional and mental health

Any treatment/therapy your relative receives should be person-centred and include any required reasonable adjustments according to the Equality Act.

Read this good practice guide here

Key message

Most treatment and therapies can and should take place in the community. The Mental Health Act states: *"Where it is possible to treat your relative safely and lawfully without detaining them, this is what should happen."* Your relative (if they have capacity) or you (on their behalf as their family carer) should always ask *"What are the benefits of being admitted to a mental health service. What care and/or treatment is being offered that can't take place in the community".*

Social Prescribing

Ask your GP about social prescribing. This means 'prescribing' a social/community activity instead of just a clinical solution. It is an early intervention treatment to address social and emotional needs such as loneliness/isolation and prevent a deterioration in emotional and mental health. Your relative's GP refers your relative to a Social Prescribing Advisor who develops a personalised action plan to improve your relative's health and well-being. This may involve support to access local opportunities and activities. Social prescribing can also help with physical health conditions, e.g. membership of a gym will help with weight management.

Read this article for more information on social prescribing

> ***"… most of them have histories of past adverse life events and significant trauma but there is little evidence of any trauma informed care and plenty of evidence of people being re-traumatised during their hospital stay…"***
>
> Source: Baroness Hollins in her letter dated 18th December 2020 to The RT Hon Matt Hancock MP, the then Secretary of State for Health and Social Care.

Trauma Informed Care

Ensure that Trauma Informed Care (TIC) is part of your relative's care, support and/or treatment. Trauma results from exposure to an incident or series of events that is emotionally disturbing or life-threatening. Examples of events that may be traumatic include use of restrictive interventions, placement breakdowns, abuse (physical and psychological), continuously being exposed to an environment which contributes to sensory overload. Instead of asking the question "What's wrong with you", trauma informed care asks, "What happened to you".

Follow this link for further information

'4 Rs' for Trauma Informed Care

1. 'Realisation' about trauma and how it can affect people/groups. There are situations where people experience trauma as a group, for example in some of the highly publicised cases of abuse such as Winterbourne View. Everybody within the service was affected, regardless of whether they were being directly abused or not.

2. 'Recognise' the signs. Being easily startled or frightened, behaviour described as challenging, feelings of guilt and shame.

3. 'Respond' to the trauma. Provide safe, nurturing, empathetic care and support.

4. 'Resist' retraumatisation.

R **Realisation**
R **Recognise**
R **Respond**
R **Resist**

This animation from CQC which includes how the use of restrictive interventions reminded somebody of the abuse they had experienced - watch here

This infographic describes the effects of trauma, how retraumatisation happens and what can help

Read this factsheet Understanding the effect of trauma on health

This trauma informed toolkit is for family carers

Read this blog about Ben's experience following abuse at Winterbourne View and a trauma informed care approach

Respond is a national charity providing therapy and specialist support services to people with learning disabilities, autism or both who have experienced abuse, violence and trauma

Read the Challenging Behaviour Foundation's report "Broken" about how trauma impacts on family carers and their relatives:

Eye movement desensitization and reprocessing (EMDR) is recommended by NICE as the first treatment for people with symptoms of post-traumatic stress disorder and there is some evidence that people with a learning disability, autism or both can benefit from this therapy. The approach is based on recognising that the thoughts, feelings and memories associated with a traumatic event can get stuck and make it hard to move on. EMDR aims to help the brain to process distressing memories and reduce their influence.

Complementary and alternative therapies, e.g. massage, mindfulness, weighted blankets: read more

Music or dance therapy. These therapies can be useful if your relative finds verbal communication difficult:

- More information about music therapy
- More information about dance therapy

Skill teaching, e.g. how to recognise stress and being aware of strategies which help such as participation in a particular activity, e.g. listening to music, walking, building resilience: read this blog about building resilience

Increase supportive networks and reduce social networks:

- Watch Zack's story here filmed as part of Mental Health Awareness Week 2001
- Read an article from Learning Disability Today

Talking therapies such as Cognitive Behaviour Therapy and Dialectical Behaviour Therapy:

- Read this article from Learning Disability Today about Cognitive Behaviour Therapy
- Read this blog about Dialectical Behaviour Therapy

Key message
Medication should not be the first and only treatment offered. If medication is suggested then it should be alongside a clear diagnosis, with a commitment to monitoring its impact and changing any other factors which could be contributing to the change in your relative's emotional and mental health, e.g. addressing a physical health need.

Follow this link for more information about medication prescribing and good practice

Your relative's rights

The Equality Act 2010 says that service providers, (e.g. hospitals, GP surgeries, dentists) must take reasonable steps to remove barriers which stop people with a learning disability, autism or both from having access to the same health care services as everyone else. This is referred to as reasonable adjustments and they are a legal requirement. People are individuals so reasonable adjustments need to be person-centred.

Click here to see a reasonable adjustments wheel

Anticipatory reasonable adjustments

- Wheelchair access
- Lifts
- Information in a range of formats, e.g. easy read

Appointments

- Timing, e.g. first/last appointment of the day
- Longer appointment
- Priority appointments

Sensory needs

- Provide a private room (to wait or on a ward)
- Plan a quieter route in and out of buildings
- Flexibility about hospital gowns, ID wrist bands

Communication

- Provide information in a person-centred format, e.g. easy read, social story, first … then, identify staff who can sign
- Use accessible language, e.g. jargon free

Proactive

- De-sensitisation work, e.g. getting somebody used to tolerating a dressing before their hospital appointment which will include minor surgery
- Nasal flu immunisation instead of a vaccination if your relative does not like needles
- Arrange a pre visit
- Do necessary paperwork beforehand to reduce the waiting time

Working in partnership

- Allow family carers to be with their relative including outside visiting hours
- Consult with family carers and other health care professionals to gain a clear understanding of what reasonable adjustments are required
- Make sure all relevant information about your relative is made available in advance, e.g. communication passport, hospital passport, health plan

Read this factsheet or watch these two video clips which are part of the Mencap Treat Me Well campaign:

- Read the factsheet from the Challenging Behaviour Foundation
- Watch the first video clip
- Watch the second video clip
- Read more about the Treat Me Well Campaign

Making reasonable adjustments for patients with a learning disability is G.R.E.A.T.

Give me more time!

Repeat yourself!

Effective communication!

Accompanied!

Think team!

The Mental Capacity Act and medical treatment

If your relative is aged 16 years old or over, health care professionals must seek their consent to any treatment first. Without proper consent their actions could be illegal.

To establish whether your relative has capacity to consent to treatment, a GP or other medical professional must carry out an assessment. For your relative to be judged as having capacity they must be able to:

1. Understand the information given to them to make a decision e.g. what the test is, why they need it, what it will involve, what are the benefits or its risks etc.
2. Remember that information long enough to be able to make a decision
3. Use the information given to them to make a decision
4. Communicate their decision. This could be using words, photos or sign language - whichever way they usually communicate.

Health care professionals can support your relative's involvement in any decision making by:

- Communicating using a method they understand
- Giving them more time to process the questions
- Seeing them in familiar surroundings such as their home
- Seeing them at a time they are likely to be responsive

If your relative is over 16 years and has been assessed as having the capacity to make a particular decision and can understand the risks and benefits but chooses to refuse medical tests, the professionals or you will have to respect their decision and not force them to change their mind.

If your relative has been assessed as not having capacity to make the decision for themselves, then others will have to act in their best interests. This involves looking at what would happen if they did not have the recommended medical treatment and the alternatives.

It is a legal requirement for professionals to consult family carers if their relative has been assessed as lacking capacity to make a decision. Health care professionals must ask for your views (and that of others involved in your relative's life e.g. siblings) about what you think is in your relative's best interests and take this into account when making any decisions. You may not be consulted if the treatment required is considered an emergency. Steps should also be taken to involve your relative in as much of the process as possible.

Some hospitals have a Mental Capacity Act assessor. They ensure that the Mental Capacity Act is being followed by:

- Making sure that lack of capacity is not being assumed
- Breaking down each part of somebody's treatment plan to ensure that a blanket decision about capacity is not being applied
- Confirming that any decisions made are in your relative's best interests
- Involving all the relevant people, including family carers

The role of Mental Capacity Act assessor usually sits alongside the Learning Disability Liaison Nursing team and safeguarding.

Decision makers do not have to follow your views if they believe they are not in the best interests of your relative. If you disagree with the decision suggested by professionals, you can apply to the Court of Protection and a Judge will decide whether the treatment should be given.

If you want to make sure that your views are listened to by professionals, you can apply for a Deputyship to the Court of Protection. The Deputyship for Health and Welfare may allow you to make decisions about health and welfare including medical treatments on behalf of your relative if it is included in the Deputyship order.

Read Ian's story about how applying for Deputyship allowed him to address his son Adam's physical health needs:

Click here to read Ian's story

Click here for an example of a good practice flowchart

Advocacy and health

Self-advocacy

If your relative has been assessed as having the capacity to agree or disagree and they understand the benefits and risks of any proposed medical treatment, they can represent themselves. Your relative can still ask for support from you as their family carer, another family member, friend or advocate. They are entitled to ask for reasonable adjustments.

Family carer advocacy

If your relative has been assessed as lacking capacity for a particular treatment, then you can represent your relative's views unless there has been an identified conflict of interest.

Independent Mental Capacity Act Advocate (IMCA)

If there is no one available to represent your relative or there is a conflict of interest, then an IMCA advocate may be asked to represent your relative's views. Even if you have chosen not to represent your relative, the IMCA advocate should still consult you and others interested in your relative's welfare.

Independent Mental Health Act Advocate

If your relative is detained under the Mental Health Act they have a statutory (legal) entitlement to an IMHA Advocate. The IMHA Advocate can support them to raise any concerns related to their emotional, mental and physical health, e.g. the medication prescribed for their mental health, requesting dental treatment, pain related to a new (constipation) or long-term health condition (diabetes).

Further information

Use this this resource as a checklist to make sure all your relative's health needs are being met and what needs to be in place to ensure that they can access health care settings: http://www.learningdisabilityservice-leeds.nhs.uk/wp-content/uploads/2021/05/Get-Check-Out-Checklist-2020-2021.pdf

Read this resource which is part of Mencap's Treat Me Well campaign. Although it is described as a resource for people with profound and multiple learning disabilities the information is still relevant:
http://www.mencap.org.uk/sites/default/files/2019-05/PMLD_brochure%5B1%5D.pdf

Use this link for advice and guidance about physical health and autistic people. There is also information for family carers:
https://www.autism.org.uk/advice-and-guidance/topics/physical-health

This article provides a personal account of the challenges an autistic woman experiences with food and eating. She discusses the sensory aspects of eating, the relationship between anxiety and controlled eating and how these can be understood and supported by those around her:
https://www.autism.org.uk/advice-and-guidance/professional-practice/controlled-eating

This online resource hosted by the Challenging Behaviour Foundation provides information and guidance about the use of psychotropic medication to manage behaviour described as challenging. It was developed as part of the Stopping The Over Medication of People (with a learning disability, autism or both) project:
http://medication.challengingbehaviour.org.uk/

Read Autistica's report Happier, Healthier, Longer Lives here. It provides information about the emotional and mental health experiences of autistic people, the causes and what can be done to address this:
http://www.autistica.org.uk/downloads/files/Building-Happier-Healthier-Longer-Lives-The-Autistica-Action-Briefings-2019.pdf

This link provides information about trauma and support for your relative:
http://www.challengingbehaviour.org.uk/information-and-guidance/when-things-go-wrong/trauma-support/

Read NHS England's National Plan – Building the Right Support. The right care and support should promote your relative's physical, emotional and mental health:
http://www.england.nhs.uk/learning-disabilities/natplan/

This good practice guide from the National Autistic Society provides examples of reasonable adjustments for talking therapies:
https://www.autism.org.uk/advice-and-guidance/mental-health/seeking-help/asking-for-reasonable-adjustments

This link provides information about Post Traumatic Stress Disorder and Autism: http://www.autism.org.uk/advice-and-guidance/topics/mental-health/post-traumatic-stress-disorder

Visit this link from the National Autistic Society for advice and guidance about different mental health diagnoses:
http://www.autism.org.uk/advice-and-guidance/topics/mental-health

Read this guide 'Supporting people living with autism spectrum disorder and mental health problems: A guide for practitioners and providers' written by Mind:
https://www.manchestermind.org/wp-content/uploads/2018/03/autism-guide-web-version.pdf

Books Beyond Words has a series of books about emotional and mental health:
https://www.booksbeyondwords.co.uk/bookshop/mental-health

This guidance covers preventing, assessing and managing mental health problems in people with learning disabilities in all settings (including health, social care, education, and forensic and criminal justice): http://www.nice.org.uk/guidance/ng54

Read this article from Learning Disability Today about improving the opportunities for people with a learning disability to be involved in sports and the benefits:
http://www.learningdisabilitytoday.co.uk/how-can-we-get-more-people-with-learning-disabilities-involved-in-sports

This report looks at what people with a learning disability, autism or both experience when they need physical health care and treatment in hospital:
http://www.cqc.org.uk/publication/experiences-being-hospital-people-learning-disability-and-autistic-people

Behaviour described as challenging

This section of the Family Carer Advocacy Pack is about behaviour described as challenging Behaviour described as challenging is not a medical condition or a diagnosis.

It is a form of communication to express an unmet need. Everyone involved in your relative's life should be aware of their likes, dislikes, wishes, feelings values and beliefs. Your relative should have an alternative way of communicating their needs and everybody in their life should listen and respond positively to their communication.

Key message:
Knowing your relative's happiness triggers is just as, if not more, important than knowing their distressed triggers.

> ***It is not hard to explain this man's challenging behaviour – give him a decent service, treat him like a human being and try to serve him rather than process him and his challenging behaviour would disappear***
> **(McGill, 1993)**

The Mental Health Act and behaviour described as challenging

Currently, if your relative has a learning disability, autism or both they can be detained (sectioned) because of behaviour described as challenging. The Mental Health Act is in the process of being amended. If the proposed changes are approved it will mean that being detained (sectioned) due to behaviour described as challenging will not be legal without a formal mental health diagnosis, e.g. depression, psychosis.

All our information sheets are available to download free of charge because we believe that money should not be a barrier to getting the information you need when you need it.

Please see the end of this information sheet for details of how to support us.

We want to make sure our resources are helpful. Please spend a few minutes giving us some feedback: Feedback form

Formal definitions of behaviour described as challenging

Two of the most widely used definitions of 'challenging behaviour' are:

- *"Culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities".*

Source: Emerson, E (1995), cited in Emerson, E (2001, 2nd edition): Challenging Behaviour: Analysis and intervention in people with learning disabilities. Cambridge University Press

- *"Behaviour can be described as challenging when it is of such an intensity, frequency, or duration as to threaten the quality of life and/ or the physical safety of the individual or others and it is likely to lead to responses that are restrictive, aversive or result in exclusion."*

Source: Royal College of Psychiatrists, British Psychological Society, Royal College of Speech and Language Therapists, (2007), Challenging behaviour – a unified approach.

Terminology

Throughout this resource behaviour described as challenging is used because it has a formal and clear definition.

There is no medication or treatment to 'cure' challenging behaviour, instead the focus should be "what is the message?". Usually the message falls into one or more of these 5 areas:

- **P - Pain.** Your relative may be in pain and is unable to communicate this or nobody is listening.
- **A – Attention/Social Interaction.** Your relative may be feeling lonely, bored, need some reassurance or just want some social interaction. Even if the attention given is negative, it is still attention and welcomed as an alternative to being left alone.
- **S – Sensory/Self Fulfilling.** Your relative may be using a sensory or self-fulfilling behaviour due to over/under stimulation or to self soothe (e.g. rocking, spinning an object).
- **T – Tangible.** Your relative may use behaviour described as challenging to get something, e.g. a drink, something to eat, a favourite person.
- **A – Avoidance/Escape**. Your relative may display behaviour described as challenging to avoid something, for example if they are asked to do something or go somewhere they don't want to or an unpleasant feeling such as anxiety.

- Use the acronym **PASTA** to remember

Read this information from the Challenging Behaviour Foundation to see how the language describing challenging behaviour has changed over time and how the term 'challenging behaviour' can be misused:

Click here to read more

Click here to read more

Identifying the underlying cause is called functional analysis. This information from the CBF explains how functional analysis is used. Watch the video clips featuring family carers providing examples of how they used functional analysis to understand their relative's messages, including teaching new skills and other more acceptable ways of communicating:

Click here to see more on the CBF's website

"All behaviour happens for a reason and challenging behaviour is no different." Watch this animation from BILD:

Click here to watch the animation

The British Institute for Learning Disabilities (BILD) has several resources explaining why behaviour described as challenging happens, including:

1. 10 things you can do for someone who has behaviour described as challenging
   Active support
2. How to communicate effectively.
3. Building a good rapport (positive
4. interactions/ relationship)
5. The impact of the environment
   Good physical health

There is a video clip and a summary sheet for each topic

Use this link to read what NICE guidelines say should happen if your relative displays behaviour described as challenging to communicate an unmet need, including:

- Working in partnership (your relative, you (family carer), health and social care professionals
- Ensuring that everyone involved in your relative's care and support and/or treatment has the appropriate skills and knowledge related to behaviour described as challenging
- Delivering and organising effective care
- Support and interventions for family carers
- Early intervention: recognising personal (severe learning disability, communication difficulties) and environment factors (sensory integration needs) which may contribute to the development of behaviour described as challenging
- Functional assessment of behaviours
- Types of interventions: psychological, speech and language to improve communication, change in housing to improve environment, e.g. from a group home to sole occupancy

Read this CQC information sheet which describes how they check that services are providing the right care, support and/or treatment if your relative displays behaviour described as challenging as a form of communication:

Click here to read the information sheet

Read SCIE's at a glance briefing: Challenging behaviour: a guide for family carers on getting the right support for adults:

Click here to read the briefing

Read this set of 6 guides ‘Meeting the Challenge’. Guide 2 describes ‘What does good support look like for adults with learning disabilities who display challenging behaviour?’:

Click here to read the guides

Restrictive Interventions

This section of the Family Carer Advocacy Pack is about the type of restrictive interventions your relative may experience, the laws and guidance about their use, what good practice looks like and what to do if you or your relative are unhappy about the way in which restrictive interventions are being used by either a service and/or health and social care staff. Whilst restrictive interventions are typically associated with mental health services and some can only be carried out lawfully for people detained under the Mental Health Act, e.g. seclusion and long-term segregation, they do take place in community settings.

What are restrictive interventions?

Restrictive interventions are deliberate acts on the part of another person(s) that restrict an individual's movement, liberty and/or freedom to act independently in order to:

- Take immediate control of a dangerous situation where there is a real possibility of harm to the person or others if no action is undertaken
- End or significantly reduce the danger to the person or others
- Contain or limit the person's freedom for **no longer than is necessary**

(Positive and Proactive Care guidance, Department of Health, 2014)

Click here to read the full guidance

Read the summary of key actions here

Key message

Restrictive interventions should only ever be used as a last resort

All our information sheets are available to download free of charge because we believe that money should not be a barrier to getting the information you need when you need it.

Please see the end of this information sheet for details of how to support us.

We want to make sure our resources are helpful. Please spend a few minutes giving us some feedback: Feedback form

The UK Supreme Court has unanimously overruled the 2014 decision in Cheshire West in a significant judgment (UKSC 16, 2 June 2026), we are awaiting updated guidance about how to assess if someone is deprived of their liberty. Therefore some of the information in this resource is out of date and will be updated in due course.

Examples of restrictive interventions include:

Chemical restraint

Chemical restraint is the use of medication which is prescribed and administered for the sole purpose of controlling or subduing behaviour. It is different from medication prescribed for the treatment of a formally diagnosed health condition, e.g. Clonazepam for seizures.

It includes the use of rapid tranquilisation medication, also known as RT, which has an immediate sedative effect (makes you sleepy). This medication is typically given by injection but can include a tablet form. Read the MHA Code of Practice para 26.91-26.102 for guidance which should be followed.

Stopping the over medication of people (STOMP) with a learning disability, autism or both

In 2015, NHS England led a 'call to action' after reports from Public Health England, NHS Improving Quality and the Care Quality Commission raised concerns that:

- There is a much higher rate of prescribing psychotropic medication amongst people with a learning disability, autism or both than the general population
- Often more than one type of psychotropic medication in the same class is prescribed
- In most cases psychotropic medication is prescribed without a mental health diagnosis
- Psychotropic medication is often used for long periods without adequate review, e.g. to monitor its impact (are things getting better or worse) and side effects which can affect quality of life for example, sedation (extreme tiredness), weight loss/gain, constipation
- There is poor communication with family carers and between different health and social care providers

The call to action led to the introduction of the STOMP project.

This resource about the STOMP project presents as a training course, but if you view/sign in you will be able to access video clips, written information and links to further resources. It includes:

- An introduction and explanation about what inappropriate prescribing of psychotropic medication is
- Descriptions of the types of medications used and their correct and incorrect use
- How to challenge the inappropriate use of psychotropic medication
- Alternatives to psychotropic medication, e.g. positive behaviour support or trauma informed care for behaviour described as challenging

This link takes you to the Challenging Behaviour Foundation's medication pathway. This resource was commissioned by NHSE as part of STOMP. The pathway focuses on how to make sure your relative only takes psychotropic medication they need, and that they are taking it safely:

Click here for the CBF's medication pathway

Organisations/services who have subscribed to the values of STOMP may display this logo:

STOMP

Stopping over medication of people with a learning disability, autism or both

If you feel that they are not following the values of STOMP, for example your relative has been prescribed psychotropic medication without a mental health diagnosis then challenge this decision with or on behalf of your relative. If you are unsure whether an organisation/service has subscribed to the values of STOMP, ask. If they don't know about STOMP this is a concern as your relative may be taking psychotropic medication they don't need. Raise this with whoever is responsible for commissioning (paying for) your relative's care, support and/or treatment.

Seclusion

Seclusion is the supervised confinement and isolation of a person, away from other people. The person is kept on their own in an area and prevented from leaving. It is intended to be used only to contain severe behavioural disturbance which is likely to cause harm to others. It is important to recognise when seclusion is taking place to ensure that the Mental Health Act Code of Practice is followed, the restriction is lawful, and all the correct procedures are followed. The following examples are still seclusion:

- The door to a room is open, but the person is still prevented from leaving by staff in the room or staff either in or

The following examples are still seclusion:

- If the person does not know how to leave an area they have been placed in
- They feel they cannot leave, e.g. if they have been told they must stay in their bedroom between certain hours, including a threat of punishment
- Called time out, quiet time or a specific name used by a service
- Takes place in a non-designated seclusion room e.g. 'nursed in their room', sensory room, 'need to stay in the snug'
- If a person lacks capacity and does not understand that they are in seclusion and makes no attempts to leave

If a person decides to be on their own this is not seclusion, but care should be taken to ensure they do not isolate themselves for too long. Consideration should be given to why a person wants to remove themselves from a specific environment e.g. are they experiencing sensory overload, are they frightened (by something that has happened to them, or they have witnessed) or unwell.

Read the MHA Code of Practice (paragraphs 26.103-26.107) for the guidance which should be followed.

Long-term segregation

Long-term segregation is a situation where, in order to reduce a continuous risk of harm posed by the person to others, which is a constant feature of their behaviour, a multi-disciplinary review and representative from the responsible commissioning (funding the service) authority determines that a patient should not be allowed to mix freely with other patients on the ward on a long-term basis.

Long term segregation is not the same as seclusion.

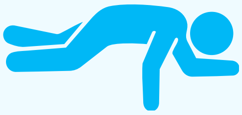
[This briefing written jointly by VoiceAbilty and Kate Mercer Training](#) discusses the role of advocacy when people with a learning disability, autism or both are kept in long term segregation. It makes a number of recommendations about how advocacy needs to improve for people in long term segregation.

Read the [MHA Code of Practice](#) (paragraphs 26.150-26.160) for guidance which should be followed.

The HOPE(S) model is a human rights-based approach developed from research and clinical practice by Mersey Care. Its goal is to reduce the use of long-term segregation sometimes experienced by people with a learning disability, autism or both. It acknowledges that admission to hospital can cause distress, resulting in behaviour described as challenging and possibly leading to an increased risk of restrictive interventions being used. This can impact on people’s wellbeing, human rights, cause trauma, impact on their length of stay in hospital and delay discharge.

If your relative is in long term segregation, ask about the HOPE(S) model.

[Read more here](#)



Physical (manual restraint)

Physical or manual restraint is the use of physical contact which is intended to prevent, restrict or subdue movement of any part of a person’s body, e.g. two staff holding a person on either side whilst seated, two staff holding a person on either side and walking them to or away from somewhere.

Read the [MHA Code of Practice](#) (paragraphs 26.69– 26.74) for guidance which should be followed. If all other options have been explored and physical restraint is considered necessary, it must still be done in the least restrictive way and only carried out by trained health and social care professionals.

Environmental restraint

Environmental restraint is the use of obstacles, barriers or locks to prevent a person from moving around freely, e.g. seating a person against a wall and placing a table in front of them, doors with keypads with only staff having access to the code.

Psychological restraint

Psychological restraint involves depriving a person of choices, controlling them by not allowing or making them do something, or setting limits on what they can do. It includes the use of threats and coercion.

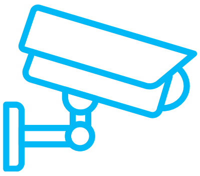
Mechanical restraint

Mechanical restraint is the use of a device which is intended to prevent, restrict movement of any part of a person’s body, and is for the primary purpose of behavioural control, e.g. strapping somebody into a wheelchair or posture support chair to prevent them from getting out, arm splints that keep a person’s arms straight (stop them bending at the elbow to reach something or hit themselves), handcuffs, spit hoods and restraint belts.

Read the MHA Code of Practice (paragraphs 26.75- 26.87) for guidance which should be followed.

Clinical holding

Clinical holding is the use of physical intervention to support the assessment or delivery of clinical (medical) care and treatment to a person who is unlikely to be co-operative such as holding an arm during a vaccination. It should only be used after other options have been considered and tried, including any reasonable adjustments which may make the experience easier. For example, if somebody is nervous about injections, their flu vaccination can be given nasally.



Technological surveillance /observations

Technical surveillance includes equipment such as pressure pads, closed circuit television, or door alarms. It is used to alert staff that a person is trying to leave or to monitor their movement. This may trigger the use of restraint, e.g. a door alarm sounds which results in staff physically restraining a person who is trying to leave. Observations of a person by staff are still considered a restrictive intervention as it is an invasion of their dignity and privacy however it may be required to maintain safety. The level of observation should depend on the person's individual history, risk and behaviours described as challenging, for example related to self-injurious behaviour.

The Restraint Reduction Network and the British Institute for Human Rights have produced a report and poster explaining the use of surveillance and how it impacts on human rights:

Click here to read the report

Click here to view the poster

Blanket restrictions

The MHA Code of Practice (paragraphs 8.5–8.9) defines blanket restrictions as 'rules or policies that restrict a person's liberty and other rights, which are routinely applied to everyone, or to classes of people, or within a service, without individual risk assessments to justify their application'.

This poster summarises what blanket restrictions are and your relative's rights

Read the Care Quality Commission's guide about the use of blanket restrictions in mental health services

The Restraint Reduction Network and the British Institute for Human Rights have produced a report and poster explaining the use of surveillance and how it impacts on human rights:

Click here to read the guide

Use this tool to check whether your relative is being exposed to any blanket restrictions

Deprivation of access to normal daytime clothing

A person should never be deprived of appropriate clothing with the intention of restricting their freedom of movement, neither should they be deprived of other aids necessary for their daily living. Sometimes it is standard practice within mental health services to only provide special tear-proof clothing when a person is in seclusion or long-term segregation. This is a blanket restriction. A decision such as this should only be made following an individualised risk assessment e.g. because there is a risk of shredded clothing being used to self-harm, attempt suicide or because a person has pica. Any tear-proof clothing should fit the person in a way that preserves their dignity, is not demeaning or stigmatising and where possible meets any specific cultural or religious requirements. The person should know what they need to do so that they can wear their usual and preferred clothing.

Read the MHA Code of Practice (paragraphs 26.161- 26.166) for guidance which should be followed.

Police attendance

Some services choose to use the police as a resource when they are unable to manage behaviour described as challenging. This includes the use of Tasers. A home office report found from April 2017 to March 2018, there were 18,000 incidents involving a Taser (actual discharge or threat, e.g. drawing Taser from holster or pointing it). Of these 2,400 incidents involved people with a mental health diagnosis which includes people with a learning disability, autism or both.

Read the College of Policing guidance on how they should engage with people, including providing support to health and social care professionals

Read the protocol Police Use of Restraint in Mental Health & Learning Disability Settings It recognises that police involvement can be terrifying, make a person more anxious, leading to an increase in behaviour described as challenging, cause trauma, or contribute to a traumatising or retraumatising effect.

When a situation is poorly managed it can escalate and lead to more than one restrictive intervention being used. This can result in a cycle of behaviour described as challenging which is difficult for the person and staff to come back from.

Read this scenario:

Gabe is a young man who was admitted to a mental health service the previous night. He has a severe learning disability and autism. He is finding the environment challenging, due to loud noises, the type of lighting, no access to a bath (only a shower), and the behaviour of other people on the ward. He is 29 years old and since he was 3 years old he has always had 2 slices of toast, 2 eggs and a drink of tea for breakfast. He uses sign to communicate but the two staff who can sign are not at work today. He is in the dining room for breakfast and is trying to explain to staff he would like 2 slices of toast, 2 eggs and a drink of tea. He has managed to help himself to two slices of toast but this was not received well. There is a system, and it does not include leaping out of your seat and helping yourself. He starts to wander around the dining room signing eggs, drink of tea. He is asked to return to his seat but refuses. Physical intervention is used to try and return him to his seat. But holding his arms means he cannot use his hands to sign. His ability to communicate has been taken away. He becomes very distressed and in an attempt to free himself he bites one of the staff. Now, instead of taking him back to his seat, it is decided to remove him from the dining room to a quiet area. He is taken down the corridor, kicking, screaming, crying and trying to bite again. Two more members of staff become involved, and Gabe is now restrained on the floor. He is terrified and continues to try and break free. It is agreed that he should be moved to a seclusion room. Staff manage to get him into the room and shut the door. He is now so distressed he starts to bang his head on the door. It is decided that he needs rapid tranquilisation. Once Gabe recovers from the effects of the medication, he comes to the window of the seclusion room. He is hungry, thirsty and confused. Staff open the door, and he starts to sign egg, drink of tea but nobody understands him. He starts to get agitated again so staff shut the door to the seclusion room. Gabe starts banging on the door. He wants to be allowed out, but staff have decided not to allow this. He is given water in a plastic cup. Gabe doesn't drink water and he needs a straw to drink all fluids. There is information in his care and support plan – about the eggs, toast, drink of tea, bath not shower, the need for staff to sign, that he is tactile defensive which means he finds touch extremely uncomfortable

Key issues relating to restrictive interventions:

- If your relative does not have the capacity to agree to the use of restrictive interventions, the Mental Capacity Act must be followed, including making best interest decisions and using the least restrictive option
- If the restrictions imposed on your relative meet the threshold for a Deprivation of Liberty an application to the Court of Protection may be necessary.

Read this Deprivation of Liberty Safeguards (DOLS) guide by SCIE for further information including case studies

- Depending on the circumstances the inappropriate use of restrictive interventions may be unlawful. Following an investigation, a range of charges could be considered including:
    - assault or battery (if a person has the mental capacity to refuse the proposed restrictive practice)
    - willful neglect or ill treatment of people lacking mental capacity (an offence undersection 44 of the Mental Capacity Act)
    - false imprisonment

Legal action may be possible to prevent further breaches of a person's rights. You or your relative can seek independent advice about how these laws apply to individual circumstances.

- The inappropriate use of restrictive interventions can have serious and fatal consequences. After the death of their son Seni following the use of force in a mental health service, the Lewis family campaigned to change the law which resulted in the introduction of the Mental Health Units (Use of Force) Act 2018.

Watch this video and read this co-produced report from the Advonet Group and Change which includes stories of people's lived experience of restrictive interventions and the impact it has had on them and their family farers/members:

Click here to watch the video

Click here to read the report

The culture and environment of services can create the situations where restraint is used. If people are not listened to or given the opportunity to have a say in their care, have nothing to do or no-one to talk to, tensions can rise, and people may become frustrated and distressed. Over-crowding, blanket or arbitrary rules and restrictions, and not being able to go out, all add to the pressure. Reducing the use of restraint starts with getting the quality of care right.
(Source: Restraint in mental health - What the guidance says)

Read the full report by Mind and Network here which includes information about restraint, people's experiences, official guidance, good practice and campaigners' stories

The Equality Act

Where there is a disproportionate use of force against people with a learning disability, autism or both this breaches the Equality Act 2010 as disability is a protected characteristic

What does good practice look like

If your relative is at risk of the use of restrictive interventions in a mental health or social care service, they should have a behaviour support plan.

The Positive and Proactive Care Guidance, Department of Health, 2014 NICE guidelines and the Mental Health Act Code of Practice all emphasise the importance of involving your relative and their family carer in the planning, reviewing and evaluation of all aspects of care and support and/or treatment, including the use of restrictive interventions.

If your relative has been assessed as having capacity they can work in partnership with those supporting them, either independently, alongside you (their family carer) and/or an advocate) to record the following information:

- What makes the behaviour more likely to happen (setting event: e.g. feeling unwell)
- What causes a behaviour to happen (trigger: e.g. being asked to go for a long walk when feeling unwell)
- The types of behaviour they use to communicate emotions such as distress, confusion, pain, anger
- What happens after the behaviour (consequence: the long walk is cancelled and your relative is told to stay in their room. As they are feeling unwell, this is a good outcome)
- What are the signs that your relative is calm
- What helps to calm things down
- What restrictive interventions will be used, if necessary, taking into consideration your relative's personal history (considering how to make this less distressing, how to ensure it does not cause trauma or retraumatise them, and considering any physical health needs such as a heart condition which impacts on their breathing).

If your relative has been assessed as not having capacity, they should still be supported to be involved in the development of their behaviour support plan as much as possible. Communication aids such as talking mats can be used to help your relative communicate their dislikes and the emotions they feel and as a family carer you will be able to provide valuable information including when they are likely to display behaviour described as challenging in response to certain situations and the best way to avoid this.

Key message:
If your relative has a good quality of life then the risk of behaviour described as challenging and therefore the use of restrictive interventions will be reduced.

It is important that you and your relative know and recognise what restrictive interventions are. They can easily become an established feature of your relative's care, support and/or treatment. For example, staff shortages mean that your relative must go to their room every evening at 8.00 pm – this is a blanket restriction.

Use this booklet co-produced by Speakup Self Advocacy and people who have first hand experience of restrictive interventions to explain restrictive interventions to your relative, if appropriate. It starts from a human rights point of view, helps people understand their restrictions and be more involved in developing least restrictive options, decide when a restriction is fair or unfair, how people want to be supported and change the way someone is restricted. It also includes information about who to speak to if there are any concerns about the way restrictions are used

Restrictive intervention reduction programmes

The Mental Health Act Code of Practice (2015) expects services to commit to reducing restrictive interventions. Here are some of the projects which are trying to achieve this:

This link takes you to the Restraint Reduction Network website

This report summarises some of the projects which are being introduced to reduce the use of restrictive interventions

This link provides more information about Safewards

For more information read the Challenging Behaviour Foundation's Reducing the use of restraint, seclusion and other restrictive practices here

Further information

Mental Health Act Code of Practice:
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/435512/MHA_Code_of_Practice.PDF

Read this guidance “Let’s talk about restraint - Rights, risks and responsibilities” from the Royal College of Nursing:
https://restraintreductionnetwork.org/wp-content/uploads/2016/11/Lets-talk-about-restraint.pdf

Positive risk taking

This section of the Family Carer Advocacy Pack is about positive risk taking and how risk assessments should enable your relative to do things instead of preventing them. The Mental Capacity Act says everbody aged 16 years old and over is entitled to make their own decisions and if they can't there is a process which should be followed which ensures that any decisions made on their behalf are in their best interests. People should always be supported to be involved in as much of the decision-making process as possible.

Safety versus happiness

There is a difference between keeping somebody safe and preventing them from being independent, allowing them to make choices and have control over their life. Unnecessary restrictions will ultimately impact on quality of life and could cause a decline in emotional and mental health and/or increase in behaviour described as challenging.

If your relative expresses an interest in doing something, the starting point should always be 'how can we make this happen'. A risk assessment should be a way of identifying what needs to happen to ensure your relative can do whatever it is they want to do, not to justify why they can't.

The Mental Capacity Act says that if your relative has the capacity to make a certain decision at a certain time then they should. This does not mean that as a family carer you cannot give advice, outline the benefits and risks of making a certain decision. Everyone asks for advice or a different view when making decisions and sometimes an opinion is given even if it isn't asked for. The pros and cons are weighed up using the information to hand and then a decision is made. This process should be no different for your relative.

> ***"What good is it making someone safe, if it merely makes them miserable?".***
> **(Source: Justice Munby, 2010)**

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We want to make sure our resources are helpful. Please spend a few minutes giving us some feedback: Feedback form

Read this blog about risk assessments and the Mental Capacity Act

If your relative has shown an interest in a particular activity (e.g. going swimming) but they have been assessed as not having the capacity for instance to weigh up the pros and cons of this activity, this should not be a barrier to participation. Those who know them well (e.g. you as a family carer, other family members, friends, paid support staff) can provide information about past experiences, what worked and what didn't work, solutions that have been identified. Think about the following:

- What does your relative want to do and why, e.g. go swimming because it is an activity they used to enjoy
- If it is something that your relative used to do and it stopped, question why this happened. This provides useful information about what worked and didn't work. For example, if it stopped because there was an incident this can be explored further: was it just one incident, were there a number, what happened, was there any reflection to identify the cause?

Positive Risk Taking
By Social Care Institute for Excellence (SCIE)

Watch this video clip from SCIE about how positive risk-taking enabled Michelle to continue to participate in an activity she enjoyed, despite the first attempt resulting in behaviour described as challenging. (starts at 10:19)

- Carry out a visit to the proposed location. Those who know your relative well will already be familiar with factors your relative may find challenging e.g. parking, entering a building, lighting, noise levels, waiting
- Identify a named person from the location who might be able to support you to find solutions, and help to arrange for instance reserved parking, entering the building via a different way, using the facility at a quiet time, booking in advance to avoid waiting. Remember that the Equality Act 2010 entitles your relative to reasonable adjustments
- Personal reasons should not influence whether your relative participates in their chosen activity, e.g. if paid support staff do not like swimming or they think your relative takes too long to get undressed/dressed
- Risk can change over time. For example, when somebody first learns to drive their risk of having an accident is higher and this is acknowledged by the insurance premium they must pay. Over time, with experience this risk decreases. The same principle applies when introducing your relative to new activities. Initially there needs to be more planning, additional staff, but over time as they become familiar with a situation any risks are likely to reduce
- What barriers are there related to resources (e.g. staffing, cost, transport)? Remember the Care Act places an obligation on local

authorities to follow the concept of wellbeing which includes participation in recreational activities.

- Control by your relative over their day-to-day life, physical and mental health and emotional wellbeing

Benefits of positive risk taking

1. Opportunity to develop new skills
2. Builds confidence and self-esteem
3. Teaches responsibility
4. Promotes learning from experience
5. Sense of achievement and success (for your relative and those involved in supporting them)
6. Encourages independence, choice and control
7. Demonstrates that trying new activities can be a positive experience
8. Can result in opening up other opportunities, increase social experiences and community presence
9. Positive impact on emotional and mental health and depending on the activity, physical health

Making it happen

By The Challenging Behaviour Foundation

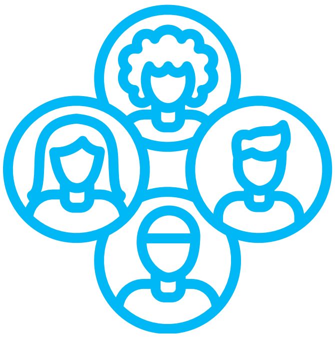
Read this fact sheet from the Challenging Behaviour Foundation which includes a matrix to help identify risk, the level of risk and how to find solutions

Read this report about Positive Risk Taking

Read this webpage from Skills for Care which includes a video about supporting services to manage risk taking

Transition from Children's to Adult Services

This section of the Family Carer Advocacy Pack is about the transition between services when your relative turns 18.



Poor transition planning from children to adult services can contribute to families and their relatives ending up in crisis (mental health and/or an increase in behaviour described as challenging) resulting in admission to a mental health service. For some families and their relatives, admission to an adult mental health service is suggested as a way of establishing what type of care and support is required. However, discussions and planning should have started in school year 9 (aged 13-14 years old), long before they reach adulthood.

10 things family carers and their relative need to think about

1. Will your relative continue to remain in education?

Read this information from Contact about your relative's rights to further education and training, including retaining their EHC plan until aged 25 years old

This link from Mencap provides information about your relative's options if they decide to remain in education

2. Will your relative take up employment (paid or voluntary)?

Visit the British Association for Supported Employment (BASE) website which aims to improve the employment rates of disabled people

3. If education, training or employment are not appropriate what will your relative do instead?

4. Who will commission and fund any services and support?

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5. Where is your relative going to live e.g. remain in the family home, residential school/college, supported living?

6. How will your relative's health needs be met? Your relative will no longer have a paediatrician coordinating their medical needs. Who will do this instead? How will their mental health be maintained? What alternative will be offered instead of CAMHS, child psychologist?

Read these top tips for professionals about supporting transition from CAMHS to adult services

7. What financial changes will take place for your relative and you (family carer) e.g. change in entitlement to child benefit if your relative leaves full time education)?

8. Is there sufficient, up to date information, recorded about what your relative needs to live a good quality of life as an adult, e.g. person centred plan including their likes, dislikes, wishes, feelings, values, beliefs and ambitions, communication passport, health action plan?

9. If your relative requires specialist equipment, e.g. communication aid, mobility equipment who will continue to provide these?

10. If you have not already addressed this when your relative reached 16 years old have you thought about deputyship depending on your relative's level of capacity to ensure that you are still able to be legally involved in decisions affecting your relative?

Watch this video from family carer Jenny about what she has learned from her son's transition

Read these 6 quality statements from NICE which should be followed to ensure a successful transition for your relative from children to adult services:

Statement 1 Young people who will move from children's to adults' services start planning their transition with health and social care practitioners by school year 9 (aged 13 to 14 years), or immediately if they enter children's services after school year 9.

Statement 2 Young people who will move from children's to adults' services have a coordinated transition plan.

Statement 3 Young people who will move from children to adults' services have an annual meeting to review transition planning.

Statement 4 Young people who are moving from children to adults' services have a named worker to coordinate care and support before, during and after transfer.

Statement 5 Young people who will move from children to adults' services meet a practitioner from each adults' service they will move to before they transfer.

Statement 6 Young people who have moved from children to adults' services but do not attend their first meeting or appointment are contacted by adults' services and given further opportunities to engage.

Read the full guidance here which explains how each quality statement translates into outcomes

The Children and Families and the Care Act places a statutory (legal) responsibility on local authorities to ensure a successful transition from children to adult services for your relative: Read more here

Follow these links from the Challenging Behaviour Foundation:

Click here for a factsheet

Click here for more information about planning for the future

Key message:
There should be no gap in services during your relative's transition between children and adult services. The local authority must continue to provide any children services until adult services are in place or it is established that your relative's needs have changed, and some services are no longer applicable or new needs have been identified and it is clear how these will be met.

The Transition Information Network (hosted by the Council for Disabled Children) publishes an online magazine, My Future Choices, which is for family carers, their relatives and professionals. It includes articles about personal experiences of transition, information and transition projects, the latest policy and charity news and resources.

NTDi has a number of tools and resources including:

- Person-centred planning
- Employment
- Independent living
- Friends, relationships and community
- Education, Care and Health planning
- Case studies and stories

Click here to find out more about the Transition Information Network

Click here to read the My Future Choices magazine

The National Autistic Society operates a transition helpline which provides information, advice and support by phone or email about:

- Rights and entitlements in relation to transition planning, including education, social security benefits and community care
- How to request assessments and access support within the community
- What options are available to help make informed decisions
- Guidance and support on specific issues such as engaging young people, finding suitable provision
- Resolving disagreements

Read more about the NAS transition support helpline

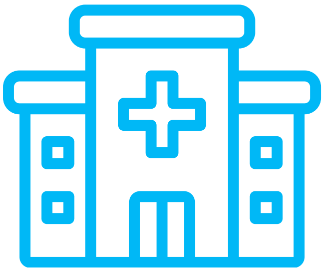
Until your relative reaches 16 years old you can advocate on their behalf when planning for their future, but they should be supported to be involved as much as possible. Post 16 years old the Mental Capacity Act will apply. When your relative goes through a Care Act assessment, they can represent themselves or do this in partnership with you (family carer), another family member or a friend. If they have been assessed as not having capacity, they should still be supported to be involved in as much of the process as possible and if there is nobody available to represent them they have a statutory (legal) entitlement to a professional independent advocate.

Key message:
Your relative's rights to a successful and seamless transition from children to adult services still apply and should not be affected if they are detained under the Mental Health Act.

Visit Contact's preparing for adult life section on their website for information about topics such as planning, making decisions, benefits and money, education health and social care: Click read more on the Contact website

Planning for discharge

This section of the Family Carer Advocacy Pack is about planning for discharge when your relative is admitted to a mental health unit.



As soon as your relative is admitted to a mental health service, planning for their discharge should begin. This is because discharge can be complicated, involve multiple agencies and take significant time to organise. Your relative should have received a thorough assessment of their needs during their detention (section) under the Mental Health Act and this should be formally recorded. This should influence what their community provision should look like, including what will prevent readmission.

Read this detailed factsheet: How do we plan for a successful discharge for my family member

What support is your relative entitled to following discharge

Section 117 aftercare:

- If your relative has been detained under a treatment section of the Mental Health Act (i.e. Section 3) then following discharge from a mental health service, they have a statutory (legal) entitlement to 117 aftercare. Section 117 aftercare is free
- The responsibility for providing 117 after care lies jointly with the Health and Local Authority where your relative was ordinarily living before being detained
- Although the duty to provide after care begins when your relative leaves the mental health service, the planning of after care should start as soon as they are admitted
- 117 aftercare should be person centred and its main purpose is to prevent the risk of readmission to a mental health service
- What and how 117 aftercare will be delivered should be part of discharge planning discussions and recorded in an aftercare plan.
- It should address the following:
    - continuing mental health needs and/or behaviour described as challenging (if this was related to your relative's detention/section)

All our information sheets are available to download free of charge because we believe that money should not be a barrier to getting the information you need when you need it.

Please see the end of this information sheet for details of how to support us.

We want to make sure our resources are helpful. Please spend a few minutes giving us some feedback: Feedback form

  - the psychological needs of your relative and, where appropriate, your needs as a family carer
  - daytime activities including education, further education, training and employment
  - appropriate accommodation
  - identified risks and safety issues
  - any specific needs arising from, for example, a sensory impairment
  - if relevant, any specific needs arising from drug, alcohol or substance misuse
  - social, cultural and spiritual needs

    transition planning, if approporiate, from children to adult services under the Children and Families Act
  - assistance in welfare rights and managing finances
  - involvement of authorities and agencies in a different area, if your relative is not going to be living locally
  - the involvement of other agencies, for example the probation service
  - if your relative's discharge is conditional the restrictions that will apply
  - a crisis plan in case your relative's mental health and/or behaviour described as challenging deteriorate
- Your relative should receive a copy of the completed aftercare plan. The plan should be clear about the services which are under Section 117 provision
- A separate care and support plan under the Care Act 2014 should document the services which are not subject to section 117 because these will be subject to financial assessment
- 117 aftercare only covers your relative's emotional and mental health – it does not provide support for any physical health needs

If your relative already has an Education, Health and Care (EHC) Plan this should be updated to reflect their needs or alternatively you (family carer) may request that your relative is assessed for an EHC Plan.

For further information read this brief guide from CQC

- Your relative should be involved in all discussions and meetings. You (family carer), their nearest relative (if this is a different person) can also be involved. Your relative is also entitled to representation from an Independent Mental Health Act advocate and if appropriate an Independent Mental Capacity Act advocate
- 117 aftercare plans should be reviewed (at least 6 monthly during the first year of discharge)
- There is no specified time period for 117 aftercare. It should only end when both the health and Local Authority agree and are satisfied it is no longer required. Your relative, you (family carer) and their professional advocate (if they have one) should also be involved in this decision

Ask the mental health service your relative is using if they have a leaflet explaining 117 aftercare.

Read information from Mind on section 117 aftercare

Read information from Rethink Mental Illness on section 117 aftercare

Read information from Rethink Mental Illness on Section 117 aftercare and personal health budgets

The Care Act amends Section 117 MHA and defines 'after care services' as services which:

- Meet a need arising from or related to the person's mental disorder and
- Reduce the risk of a deterioration of the person's mental condition (and, accordingly, reducing the risk of the person requiring admission to a hospital again for treatment for the disorder)

What services should be included in an aftercare plan should focus on this definition when it is first developed and written and then when it is updated at every review.

Regardless of whether your relative was a voluntary or detained patient, they are entitled to support using the principles from the Health and Care Act and Integrated Care Systems.

Read more about the Health and Care Act and Integrated Care Systems:

Click here to read information from the King's Fund

Click here to read information from NHS England

Your relative may be entitled to support through the Care Programme Approach now referred to as the Community Mental Health Framework.

The change will not affect the care, support and treatment your relative receives if they are entitled. Your relative will have a plan and a named coordinator (usually a nurse, social worker or occupational therapist) who will provide help, support and advice about matters, including:

- Medication
- Finance
- Housing
- Support
- Support for your relative to access the community

The plan should include information about how to minimise the risk of your relative's mental health deteriorating (getting worse) and what should happen in an emergency or crisis.

Read more about the Care Programme Approach:

Click here to read more from NHS England

Click here to read more from Rethink Mental Illness

Receiving section 117 aftercare and/or being under the Care Programme Approach does not replace your relative's entitlement to a 'needs assessment' (under the Care Act).

Read SCIE's information about the Care Act, the assessment process and eligibility

Housing

Inappropriate housing may have contributed to a decline in your relative's mental health and/or behaviour described as challenging which led to the need for a mental health service. For example living in a care home with people they did not get on with, or in an area which was not safe and left them vulnerable to abuse or isolated. ("Not having the right home – whether that is general needs housing, supported housing or residential care – can also contribute to people having unmet needs and being admitted into a mental health hospital." Source: Building the Right Support Action Plan) This means that before your relative can be discharged they will need alternative housing which meets their needs.

Data from Assuring Transformation in April 2022 identified that 45% of discharges from mental health services were delayed because of a lack of suitable housing. The Building the Right Support Action Plan has acknowledged this, and increased funding is available. However, there is currently a national housing shortage, so more people are competing for the same housing, including people with a learning disability, autism or both. Click here to read more about the Assuring transformation data

There are several housing options available for your relative:

- Registered Care Home
- Rented Social Housing
- Rented Private Sector Housing
- Shared Ownership
- Social Housing from Capital Programme
- Home Ownership and the Use of
- Discretionary Trusts
- Buy to Let
- Remaining in the Family Home and Other Family Solutions

Like all aspects of your relative's care and support and/or treatment, accommodation should be person centred. Use all your relative's assessments to develop a 'housing specification'. Think about all the things that are important to your relative. Here are some things to consider:

Property

- House
- Flat
- Semi-detached
- Detached
- Purpose built
- Adapted

Who will your relative live with

- Live alone
- With a friend
- How many people
- Level of support (staff) and size of house
- Does your relative have/want a pet
- In the family home (with or without adaptions)

Location

- City centre
- Town
- Village
- Countryside
- Close to preferred activities and amenities
- Public transport
- How will support staff get to work
- Main road, side road
- Terrain e.g. is the area hilly, on a slope, flat
- Neighbourhood e.g. is it safe, well lit
- What else is nearby that might impact on your relative positively (e.g. cinema) or negatively (e.g. dog kennels if they have a fear of dogs or find barking difficult because of their sensory needs)

Design

- Sensory considerations e.g. lighting, soundproofing
- Any safety requirements e.g. ability to turn off water independently from source
- Specialist furniture, e.g. Velcro curtains, rip proof mattress
- Parking (for your relative and their support staff)
- Number of rooms
- Size of rooms
- Garden
- Technology
- Privacy e.g. height of fence

Resources about housing

From the Challenging Behaviour Foundation:

1. 8 ways to get a house includes a description of each type of housing option, the advantages and disadvantages of each option, a case study illustrating each option and a jargon buster

2. Planning your house includes information about where to start, funding options and case studies

3. Specialist equipment and safety adaptations

Visit the Council for Disabled Children's website and download their No place like home - a housing and support guide:

This link takes you to the Government's Own your Home website which includes information about shared ownership for people with long-term disabilities

My Safe Home is an organisation which provides support for people with a learning disability, autism or both to access a mortgage through the HOLD scheme

Read this factbook from Home Ownership for people with Long-term Disabilities (HOLD)

My Great Life is a not-for-profit social enterprise which specialises in accommodation for people who have higher levels of support in the community and may need adaptations and specialist staff including people who are being discharged from mental health services

Although this link 'Homes not Hospitals' is for social workers, it provides information "to support social workers to work preventatively, strengthen legal literacy and more specialised ways of working to avoid admissions to hospital, support, advocate and challenge on behalf of people currently in assessment and treatment units or restrictive settings to enable a return to home as soon as possible"

The right support

If the community care and support your relative was receiving did not meet their needs, e.g. the level of support was inadequate, support staff did not have the relevant training and skills, successful discharge and reducing the risk of readmission to a mental health service may require additional funding. Part of your relative's assessment during their time in hospital should have identified the level of support and skills staff require, e.g. able to communicate using sign language, understanding of functional analysis. Depending on how long your relative has spent in a mental health service, the transition back to their community may have some teething problems. Everybody supporting your relative should be prepared for this and there should be contingency plans in place, e.g. funding for additional staff, a crisis plan.

What if my relative is ready for discharge but they have nowhere to go

If the rules for keeping your relative in a mental health service are no longer met but they are still being detained in hospital, this may be unlawful. Your relative's IMHA and/or a mental health solicitor should provide help in this situation. It may be necessary to also seek help from a community care specialist or human rights solicitor. There are specialist law firms who are able to provide advice for family carers and their relatives if they want to legally challenge issues such as:

- Inappropriate detention in an ATU
- Under threat of admission to an ATU
- Unlawfully detained in an ATU because because their local authority or Clinical
- Commissioning Group haven't found them a suitable home
- Received poor or inappropriate care during detention
- Experienced human rights violations whilst in a mental health service
- Placed in a community placement that was unsuitable for their needs
- Detained subject to a legal framework which is not the least restrictive
- Experienced inappropriate aftercare provision (s117 of the Mental Health Act 1983)

Click here to go to the Irwin Mitchell Assessment and Treatment Unit solicitors webpage

The National Autistic Society is funded to provide an autism inpatient mental health casework service which:

- Offers information, advice and support by phone or email
- Explains mental health rights and entitlements to help prevent or challenge detention and secure the care and support and/or treatment needed in the community
- Helps autistic people and their families explore their options and make informed decisions
- Provides guidance and support on specific issues such as accessing advocacy, finding suitable provision in the community, making a complaint or appealing against a decision
- Works closely with and signposts to other relevant advice and support within the National Autistic Society, including education rights, transition, autism helpline, parent to parent
- Helps with preparation for meetings
- Signposts to other external services, e.g. legal support

Read more about the autism mental health casework service

Self-advocacy

If your relative has been assessed as having the capacity to participate in the discharge planning process they can advocate for themselves, including in partnership with you (family carer) and a professional independent advocate. If your relative has been assessed as lacking capacity they should still be included in as much of the planning process as possible

Family Carer Advocacy

NICE guidelines promote the inclusion of family carers in discharge planning and if you are your relative's nearest relative then you have a statutory (legal) right to be involved.

Professional Independent Advocacy

If your relative has a statutory entitlement to an Independent Mental Health Act advocate, they will be able to help and support your relative through the discharge planning process to make sure that their views are all taken into account.

Further information

Whilst this briefing is for local authorities it is useful for family carers to be aware of what financial models are available to meet the objectives of ensuring a reduced reliance on admission to mental health services through investment in community alternatives: https://www.local.gov.uk/learning-disability-and-autism-finance-briefing

The Learning Disability and Autism Community Discharge Grant is a non-ringfenced grant available to local authorities in England to help accelerate discharge of patients with a learning disability or autism (or both) from mental health hospitals into the community:
https://www.gov.uk/government/publications/learning-disability-and-autism-community-discharge-grant-2020-to-2023/learning-disability-and-autism-community-discharge-grant-guidance

Read NICE guidelines about transition between inpatient mental health settings and community or care home settings:
http://www.nice.org.uk/guidance/ng53/chapter/recommendations

Housing LIN is a network for anyone working in housing, health and social care, promoting solutions that enable everyone to live well in good quality housing:
http://www.housinglin.org.uk/

Read Mind's section on leaving hospital:
http://www.mind.org.uk/information-support/legal-rights/leaving-hospital/overview/

The Challenging Behaviour Foundation
making a difference to the lives of people with severe learning disabilities

FAMILY CARER ADVOCACY RESOURCE

Advocacy

This section of the Family Carer Advocacy Resource provides an overview of advocacy, including the different types of advocacy and how they relate to your relative.

What is advocacy?

"Advocacy is taking action to help people say what they want, secure their rights, represent their interests and obtain services they need. Advocacy promotes social inclusion, equality and social justice. "
(The Advocacy Charter, 2018)

Some people with a learning disability, autism or both may be able to self-advocate. Disability Rights UK defines self-advocacy as *"The ability to speak-up for yourself and the things that are important to you. Self-advocacy means you are able to ask for what you need and want and tell people about your thoughts and feelings. Self-advocacy means you know your rights and responsibilities, you speak-up for your rights, and you are able to make choices and decisions that affect your life."*

For more information about what advocacy is:
The Advonet Group
Cloverleaf Advocacy
Warrington Speak UP

Family Carer Advocate

Even if your relative is able to self-advocate, there may be situations when additional support may be beneficial. This could be in partnership with a family carer advocate (you or a family member), informal advocacy (a friend) or support from a professional independent advocate because there is a statutory (legal) entitlement, and the appropriate advocate will have specialist training in a specific area such as the Mental Health Act.

Click here to watch a video from The Advonet Group explaining what self advocacy is

Use this self-advocacy pack

Visit Advonet's self-advocacy webpage for more information and resources

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The UK Supreme Court has unanimously overruled the 2014 decision in Cheshire West in a significant judgment (UKSC 16, 2 June 2026), we are awaiting updated guidance about how to assess if someone is deprived of their liberty. Therefore some of the information in this resource is out of date and will be updated in due course.

There is no formal definition for family carer advocacy but the importance of their involvement, either alongside their relative or on behalf of their relative is acknowledged, for example in Acts such as the Mental Capacity Act.

Key Message
All types of advocacy are of equal value. What advocacy is used, and when, depends on your relative and the situation. What is common to all types of advocacy is that your relative is always at the centre of the advocacy process.

What your relative can expect from a professional independent advocate

Read how advocates from the Advonet Group hold themselves accountable by providing clear information about what support they are going to provide, how they will provide it and by when, whilst always considering ways to support people to develop their self-advocacy skills.

Click here to read the Advonet Group's Community Advocacy Agreement

Click here to read the Advocacy QPM Code of Practice

Advocacy Charter

Currently, advocacy is not regulated but most advocacy organisatons have signed up to the NDTi Advocacy Charter and NDTi Advocacy Quality Performance Mark (QPM). There is a cost attached to qualifying for the NDTi Advocacy QPM and for some small organisations this may be a barrier, despite providing a good quality service.

Click here to read the Advocacy Charter

Click here to read more about the Advocacy Quality Performance Mark

You can check the quality of the service you and/or your relative is receiving using this assessment book

Advocacy QPM
Recognising quality
in independent advocacy
an NDTi Programme

Who funds advocacy and how this impacts on your relative

The responsibility to fund statutory advocacy lies with the local authority where a service is located. This means that if your relative's hometown is London, but they are currently in a mental health service in Leeds, the advocacy they receive will be from an organisation in Leeds.

Following discharge from a mental health service, if your relative is entitled to ongoing statutory advocacy but they are now in a different authority they will have to be referred to a local service and develop a relationship with a new advocate.

Within each authority, different organisations will have the contract to provide different types of advocacy to different services. This can lead to disjointed advocacy for your relative. For example, if they require support from an Independent Mental Health Act (IMHA) Advocate and an Independent Mental Capacity Act (IMCA) Advocate but two different organisations have been appointed to provide each type of advocacy on one hospital ward, your relative could find themselves with two advocates from two different organisations.

Independent hospitals do not always provide statutory advocacy and the advocacy they do provide may be in house. In house advocacy means that the advocate works for and is paid by the independent hospital. This can lead to concerns about whether the advocate can truly be considered independent, e.g. they may be raising a concern on behalf of your relative about the organisation which pays their salary. Or if they are the only advocate representing all the people on one ward there may be a conflict of interest. If an independent hospital does not provide statutory advocacy e.g. Independent Mental Health Act advocate, then it is the local authority's responsibility to fulfil this legal right.

How can an advocate help?

An advocate can help and support a person to:

☑ Speak up for themselves or give their views
☑ Understand the process they are going through, their rights and what choices are available to them
☑ Be part of an important decision which is being made about them
☑ Prepare for and take part in meetings and tribunals
☑ Raise queries or concerns (Read this guidance from Voiceability which provides
☑ Information for advocates about challenging decisions or actions with or on behalf of people)
☑ Access information in the format which is most suitable
☑ Access services that can support them
☑ Provide information and signpost people to other helpful services.

An advocate should not:

☒ Give their personal opinion or advice
☒ Solve problems and make decisions on somebody's behalf without first asking /
☒ Involving them
☒ Tell people what to do
☒ Make judgements
☒ Offer counselling

Instructed advocacy

Instructed advocacy means your relative can independently communicate their likes, dislikes, wishes, feelings, values and beliefs as well as the actions they would like an advocate to take, for example:

- Write a letter on their behalf
- Represent them in meetings
- Contact professionals

People who can instruct an advocate have been assessed as having the capacity (ability) to understand the role of an advocate and how they can represent them.

Non-instructed advocacy

If your relative is entitled to statutory advocacy but has been assessed as lacking capacity (ability) a non-instructed advocacy approach will be used. "Non-instructed advocacy is… taking affirmative action with or on behalf of a person who is unable to give a clear indication of their views or wishes in a specific situation. The non-instructed advocate seeks to uphold the persons rights, ensure fair and equal treatment and access to service, make certain that decisions are taken with due consideration for their unique preferences and perspectives." (Henderson, 2006) There are 4 key approaches used for non instructed advocacy:

- Rights-based approach. Your relative has certain fundamental human rights that can be defined and measured, e.g. right to family life
- Person-centred approach (find out more)
- Watching brief approach (find out more)
- Witness/observer approach. By spending time with your relative an advocate observes what they like/don't like, what makes them happy and equally if there is anything of concern which needs to be addressed.

Non-instructed advocacy considers the following questions:

- What is life like for your relative?
- What is important to them?
- What might their wishes, feelings and desires be?
- What are their rights?
- What information do other people (e.g. their family carers, other family members and friends) know about your relative's past or present preferences
- What responsibilities do other people (e.g. family carer) or organisations (e.g. social services) have towards your relative?
- Is your relative being treated fairly?
- How can your relative's involvement in decisions made about them and their life be increased?

Click here to read the non-instructed advocacy best practice guidance

Click here to read Josie's story

Non instructed advocacy should ensure your relative's voice is heard if they have been assessed as lacking capacity. Despite this family carers report that it is difficult to access skilled, non instructed independent advocates.

Types of advocacy

Statutory Advocacy

Statutory advocacy means a person is legally entitled to an advocate because of their circumstances. The local authority has a duty to ensure statutory advocacy is available to people in their area.

The following are Statutory Advocacy services:

Independent Mental Capacity Advocacy (IMCA)

If your relative has been assessed as lacking mental capacity an IMCA can provide support when a specific decision is required at a specific time including:

- When there is no family carer, other family member, friend or unpaid person to provide support
- There is a disagreement between you (family carer), other family members, friends, professionals about what is in your relative's best interests
- There are allegations, suspicions or proved incidences of abuse by the family carer, other family members or friends
- Giving or withholding serious medical treatment (e.g. cataract operation)
- A proposed change or review of living circumstances (e.g. admission to hospital)
- Safeguarding, e.g. financial or physical abuse

Care Act Advocacy

The Care Act 2014 requires the local authority to involve your relative in decisions about their care and support needs. However, if they will have substantial difficulty being involved in any of the following processes:

- A social care assessment or review
- Agreeing a social care support plan
- A safeguarding enquiry or process

and they do not have a family carer, other family member, or friend who is able to advocate on their behalf they have the right to a Care Act Advocate. The Care and Support Statutory Guidance states that:

For further information read Making Decisions: The IMCA Service from the office of the Public Guardian (OPG):

Click here to read more and/or visit this SCIE link

> ***"Many of the people who qualify for advocacy under the Care Act will also qualify for advocacy under the Mental Capacity Act. The same advocate can provide support as an advocate under the Care Act as under the Mental Capacity Act. This is to enable the person to receive seamless advocacy and not have to repeat their story to different advocates".***

Watch this video explaining the Care Act

Read this factsheet for more information

> ***"By having the same advocate for all IMCA referrals we were able to ensure that Carol received advocacy support from someone who understood her history, had knowledge of her needs and who had established a positive working relationship with the wide range of professionals involved."***
> **Warrington Speak UP**

Read Carol's full story

Independent Mental Health Advocacy (IMHA)

Your relative is entitled to an IMHA if they are:

- Detained (sectioned) under the MHA
- Under a Community Treatment Order (CTO)
- Subject to a Guardianship Order
- Conditionally discharged

An IMHA cannot provide support for your relative if they are:

- Taken to a place of safety under the MHA
- Informally held for a period of up to 72 hours under emergency 'holding powers' using Section 5 of the MHA which is to allow for a formal assessment of detention to be completed

Deprivation of Liberty Safeguards (DoLS) 2009

If your relative is being deprived of their liberty under the Mental Capacity Act, an IMCA can be appointed to protect their human rights and make sure the deprivation is:

- Lawful
- Reasonable
- In their best interests
- A Section 39A IMCA will be instructed when there is an assessment in response to a request for a standard authorisation, or a concern about a potentially unauthorised DoL

Relevant Person's Representative (RPR)

A Relevant Person's Representative is responsible for protecting a person's interests if:

- They have been assessed as lacking capacity to make some decisions for themselves, and
- They have been deprived of their liberty to prevent them from coming to harm a RPR can be a family carer, other family member or friend
- A section 39C IMCA can cover the role of the person's RPR if there is a gap between appointments
- A section 39D IMCA can support your relative or the RPR if there is a standard authorisation in place

Paid Relevant Person's Representative (PRPR)

- The local authority will appoint a PRPR if there is no family carer, other family member or friend available to
- A PRPR has the same responsibilities as an RPR

The responsibilities of the RPR or RRPR:

- Regular contact with the person they are representing
- Checking that any deprivation of liberty remains legal
- Making sure that the person's wishes, feelings, values and beliefs are upheld
- The support provided by the RPR or RRPR must be completely independent from the providers of the service your relative is receiving

More information on the responsibilities and processes of an RPR or PRPR:

Read a guide from the Department of Health

Read Julia's story

Rule 1.2 Representative

A Rule 1.2 Representative supports anyone who is being deprived of their liberty in a community or domestic setting who has been assessed as lacking capcity and needs someone to advocate on their behalf about consent to restrictions on their freedom. Usually a social worker will decide whether the role of Rule 1.2 Representative is a family carer or friend (unpaid) or a professional independent.

NHS Complaints Advocacy

NHS Complaints Advocates help people raise a complaint about any service **provided or funded by the NHS** including:

- GPs
- Hospitals
- Mental health services
- Pharmacies
- Opticians
- Dentists
- Ambulance services
- Nursing homes
- Care homes
- Home based care packages

Read this case study from the Advonet group:

The advocate:

- Helped to identify all options available to the person they were representing
- Supported their client through the process ensuring there was no further deterioration in their mental health due to the stress related to making a complaint
- Kept the organisation involved up to date with any delays because of their client's mental health to make sure this did not impact on the complaints procedure

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Non-Statutory Advocacy

Non-statutory advocacy means there is no legal entitlement to an advocate and therefore no obligation for local authorities to provide funding. Individual local authorities can decide what non-statutory advocacy - if any - they will fund. This type of advocacy is often provided by charities who work in specific areas, e.g. the Challenging Behaviour Foundation who specialise in supporting families and their relatives who have a severe learning disability and behaviour described as challenging.

Some non-statutory advocacy is provided by volunteers.

The following are non-statutory advocacy services:

Citizen Advocacy

Citizen Advocates provide one-to-one support to help people tackle any issues they are facing. Citizen Advocates may provide support in person, by telephone or by email and help people to access information, speak up and get their voice heard

Watch the Advonet Group's Meet the Citizens Advocates video to learn more

Peer Advocacy

Peer Advocates are volunteers with lived experience of using health and social care services. They share their experience and provide practical support and encouragement. Peer advocates are matched with someone who has similar needs and issues to support them to develop new skills and gain confidence.

Read about the peer advocacy provided by the Challenging Behaviour Foundation

Group Advocacy

Group Advocacy brings together people with similar needs and issues to support each other. These groups give people the opportunity to share experiences and work in partnership to raise joint concerns. Sometimes the group has a facilitator who supports the running of the group and sometimes these groups are self-supporting.

Carers Advocacy

NHS England defines a carer as "…anyone, including children and adults who looks after a family member, partner or friend who needs help because of illness, disability, or a mental health problem and cannot cope without their support. The care they give is unpaid…".

Carers Advocates can help family carers:

- To understand their rights and how to exercise them
- Access a Carers Assessment
- Communicate their own needs to people making decisions
- By attending meetings
- Raise a concern or make a complaint
- By signposting to other services that might be available to help them

Further information

Read this guide from the Challenging Behaviour Foundation about what commissioners should consider when commissioning advocacy services for people with a severe learning disability: https://www.challengingbehaviour.org.uk/wp-content/uploads/2021/03/Advocacy-guide-for-commissioners.pdf

This factsheet from Cloverleaf Advocacy provides answers to frequently asked questions about advocacy: https://cloverleaf-advocacy.co.uk/advocacy/

Read what the Care Quality Commission says about the relationship between person-centred care and support and advocacy: http://www.cqc.org.uk/publications/themes-care/rss22_02_person-centred

The Challenging Behaviour Foundation

making a difference to the lives of people with severe learning disabilities

We are the charity for people with severe learning disabilities who display challenging behaviour. We make a difference to the lives of children and adults across the UK by:

- Providing information about challenging behaviour
- Organising peer support for family carers and professionals
- Giving information and support by phone or email
- Running workshops which reduce challenging behaviour

To access our information and support, call 01634 838739, email info@thecbf.org.uk, or visit our website: www.challengingbehaviour.org.uk

www.challengingbehaviour.org.uk Tel. 01634 838739
Registered charity no. 1060714.
Reg office: The Old Courthouse, New Road Avenue, Chatham, Kent ME4 6BE