

Meeting the
challenge

Frequently
asked questions
about the law



Meeting the challenge

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Introduction

Too often people with a learning disability and behaviour that challenges are not getting their legal rights met.

This factsheet will provide you with information about your family member's legal rights in relation to social care and health provision and how to exercise these rights.

It primarily focuses on the legal rights of **adults (people aged 18 and over)**.

This factsheet has been written to accompany a series of 7 factsheets about people with a learning disability and behaviour that challenges in order to provide more of the detail on relevant aspects of the law that will help family members to ask the right questions. Although it can only provide general guidance and cannot be relied on to give a legal answer to any particular case, the aim of all the factsheets is to help ensure that people with a learning disability and behaviour that challenges get good support and are able to live fulfilling lives.

If you need further advice, or you are not sure how to resolve a problem you or your family member is facing, then you can contact a community care or mental health solicitor. You may be eligible for “legal aid” which means you would not ordinarily expect to have to pay any legal fees for advice. See the end of this factsheet for more information about legal aid.

Below the terms “duty” and “power” are used frequently. When a public body, such as a local authority, has a “duty” to do something, this means that it has a legal obligation to do it – it must do it. When a public body has a “power” to do something, this means that it can do it but it does not have to. You can still take action to persuade a local authority to exercise a “power” in your favour however, and the public body must still exercise its power rationally, reasonably and fairly.

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The principles of the Human Rights Act 1998

The laws outlined in this FAQ relate to health and social care and the duties of public authorities (e.g. local authorities or the NHS) to provide services for some people. But it is also important to keep in mind the underpinning principles of the Human Rights Act. The Human Rights Act is about ensuring that every person's fundamental freedoms and rights are protected. People with a learning disability and behaviour that challenges have the same human rights as everyone else.

Many of the accepted 'good practice' ways of working with people with a learning disability have human rights at their core. Things like person-centred planning are about ensuring the people with learning disabilities have the same rights, choices and opportunities as everybody else. There are a number of rights that are particularly relevant to people with learning disabilities, and the issues that they will face on a day-to-day basis. In particular:

- **Article 2** – the right to life: the State has a positive duty to ensure the right to life and to investigate when this may have been violated.
- **Article 3** – everybody has the right not to be tortured or suffer inhuman or degrading treatment: this means that people with learning disabilities are protected in law from abuse and from living in unacceptable conditions.
- **Article 8** – the right to respect for a private and family life: this means that people with learning disabilities have the right to have and maintain family relationships.
- **Article 14** – the right to not be discriminated against in the enjoyment of your other rights: this right helps to ensure that people with learning disabilities are not discriminated against because of their disability.

Meeting the challenge

Getting an assessment and meeting people's support needs

Assessment

1. Does my family member have a right to an assessment?

Yes. If you believe your family member requires support in any way, you should contact your local authority and request a needs assessment. The local authority has a legal duty to conduct an assessment if it appears the person may be in need of community care services. Community care services mean the kinds of services provided by a local authority to adults with care needs; for example, help around the home, support with personal care, recreational activities etc. It is a low threshold to trigger the duty to carry out an assessment – the local authority should assess if there is any realistic prospect that the person may need services.

You should make the request for an assessment in writing and address it to the local authority's adult social services department. If support is urgently required, make sure you explain this

in your letter and/or contact the social services department by phone as there will be a duty social worker available. The local authority has a power to provide urgent support before starting an assessment and while the assessment is carried out.

At the point of assessment, the person's finances are irrelevant – the local authority must carry out an assessment even if he/she has some income or capital if the low threshold set out above is met. The local authority are required to complete an assessment within an appropriate and reasonable period of time, with what is 'reasonable' depending on the facts of the case, particularly the urgency from the disabled person's perspective. Typically, a period of 4-6 weeks from the date of the request will be considered reasonable.

If you request an assessment and it has not been conducted within a reasonable period, consider making a formal complaint to your local authority. More information about how to do so is set out below.

If your relative is in urgent need of support and the local authority have not responded quickly enough to conduct an assessment, or you have made a formal complaint and the local authority has still not carried out an assessment, a community care solicitor may be able to assist you. You will need advice on whether the decision can be challenged by way of an application for judicial review in the High Court.¹

You can request an assessment from the local authority by using our template letter:

www.irwinmitchell.com/personal/protecting-your-rights/social-healthcare-law/the-care-act/care-act-factsheets-and-template-letters

1. A Judicial review is a type of court proceeding in which a judge reviews the lawfulness of a decision or action made by a public body, like a local authority.

2. Do I have a right to an assessment as a carer?

Yes. Section 10 of the Care Act provides that a carer will be entitled to an assessment if it appears that a carer needs support. The carer's assessment must establish whether the carer is willing and able to continue providing care to the disabled adult, what impact this has on the carers' wellbeing, what outcomes the carer wishes in day-to-day life, and whether he/she wishes to access education, training, or recreational activities.

Under the Care Act, the carer will have the same rights to an assessment and support as the disabled adult themselves. Therefore once a carer's assessment has been carried out, the local authority will see which of the carer's needs are eligible for support, and will then produce a support plan to meet the carer's needs. Local authorities are under a duty to meet a carer's eligible needs under section 20 of the Care Act, subject to a financial assessment.

You can request a carer's assessment from the local authority by using our template letter: www.irwinmitchell.com/personal/protecting-your-rights/social-healthcare-law/the-care-act/care-act-factsheets-and-template-letters

3. Do any experts have a role in the assessment process?

Local authorities must ensure that assessors are appropriately trained and competent whenever they carry out a needs assessment. When assessing particularly complex or multiple needs, an assessor may need the support of an expert to carry out the assessment to ensure that the person's needs are fully captured.² In addition to this, there is specific guidance for people who are deafblind or people with autism which emphasise the need for expertise when undertaking an assessment.

If your relative exhibits challenging behaviour, then he/she may need support from a psychologist or a psychiatrist. You are entitled to ask for this input in the assessment process so that a lawful assessment is conducted which will accurately identify your relative's needs. If the needs are health-related, this may indicate a need for a continuing healthcare assessment by the NHS (see above for more information).

Don't be afraid to ask for experts to be involved. It is in everyone's interests for the assessment to be thorough, so that a package of support can be put in place that fully meets the person's needs – for example, staff have the

right skills to support the person's behaviour properly and the environment is right for the person and helps minimise triggers for their challenging behaviour. If the assessment isn't thorough and the package of care is not right, there is a risk the placement could break down. If you ask for expert involvement and it is refused, and as a result you do not believe your family member is getting the support they need, then you may want to contact a community care solicitor for advice about how to challenge the assessment.

There are certain services, such as occupational therapy or speech and language therapy, which must be met if they are identified as an eligible need, but could be provided by either the local authority or the NHS. The NHS and the local authority must cooperate with one another under the NHS Act 2006 to ensure that your relative's needs for these kinds of services are met.

2. Paragraph 6.87 of the Care and Support Statutory Guidance 2014

4. Does my family member have a right to a “functional assessment”?

A functional assessment is an assessment of your relative’s behaviour, and is usually carried out by a psychologist or a behaviour nurse. These assessments are used to identify potential causes of challenging behaviour (such as aggression or destructive behaviour) so that the right support can be put in place to reduce this.

If your relative exhibits challenging behaviour, then they may well require health-related support from the NHS, for example from a psychologist or psychiatrist. Remember that the NHS and the local authority must cooperate with one another to ensure that your relative’s needs for these kinds of services are provided for.

If you believe your relative requires a functional assessment and one has not been carried out, contact your local authority to request one. Social services may then make a referral to the NHS. Although the Care Act guidance does not specifically refer to a functional assessment, any assessment must capture all of a person’s needs and must be undertaken by someone with suitable qualifications and experience, so your request cannot be unreasonably refused.

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Getting an assessment and meeting people's support needs

Support and care planning

5. Does the local authority have a duty to meet my family member's needs?

The local authority has a duty to meet all of your family member's eligible needs, providing that they are then financially eligible for support following an assessment. Local authorities are entitled to charge for the care they provide, depending upon the financial means of the individual. If your family member is not financially eligible, you can still ask the local authority to arrange for the care anyway, and pay towards that care.

During the assessment process, the local authority should firstly identify all of your family member's needs. The social worker conducting the assessment should involve the person in every aspect of his/her own assessment, so far as this is possible. If the person has substantial difficulty in understanding the assessment process and if there is no suitable

person (such as a family member) who can help them understand it, they are entitled to support from an independent advocate. All of his/her needs should be recorded clearly in the assessment. The assessment should record all needs that would be present if the person was not getting any family support. Essentially, the social worker conducting the assessment should identify any and all needs that could be satisfied by providing a community care service.

When carrying out the assessment, the local authority will need to have regard to the 'wellbeing principle' as set out in the Care Act. This means that the local authority will need to promote that person's wellbeing when carrying out the assessment and meeting their needs. The social worker will need to consider such matters as the person's dignity, their health and wellbeing, their ability to participate in work or training, and their social or family relationships. The assessment should be person centred and start from the assumption

that the individual will understand their needs best.

Once the local authority has carried out the assessment, it will need to determine which of the person's needs are "eligible" for support. In order to do this, the local authority will refer to "eligibility criteria". The Care Act has introduced national eligibility criteria, which means that all local authorities will need to adhere to the following rules as a minimum.

To have eligible needs, the following should apply:

- The needs must arise from or be related to a physical or mental impairment or illness;
- As a result of the needs, the adult must be unable to achieve two or more of the following outcomes:
 - > Managing and maintaining nutrition;
 - > Maintaining personal hygiene;

- > Managing toilet needs;
 - > Being appropriately clothed;
 - > Being able to make use of the adult's home safely;
 - > Maintaining a habitable home environment;
 - > Developing and maintaining family or other personal relationships;
 - > Accessing and engaging in work, training, education or volunteering;
 - > Making use of necessary facilities or services in the local community including public transport, and recreational facilities or services; and
 - > Carrying out any caring responsibilities the adult has for a child.
- As a consequence of the above there is, or is likely to be, a significant impact on the adult's well-being.

The definition of the word “unable” in the second bullet point above is important. The Regulations state that “unable” to achieve an outcome actually means that without assistance, the individual would be in “significant pain, distress or anxiety”, or if it takes them significantly longer.³

Provided that your relative's needs are ‘eligible’ for support under the criteria above, the local authority must meet those needs.

How the local authority will meet your relative's eligible needs must be set out in a “care and support plan”. A care and support plan is a detailed document setting out what services will be provided, how they will meet your relative's needs, when they will be provided, by whom, with what frequency etc. You or your family member is entitled to see a copy of it and the local authority should ensure that you / your family member is happy with the care and support plan before it is finalised. The Care Act provides that the care and support plan must be person centred and person led.⁴ The plan should be reviewed regularly once it is in place, which should be at least annually or more often if necessary.

At the bottom of the care and support plan there must be a sum of money, called a “personal budget”. A personal budget is an allocation of funding by the local authority. The amount allocated must be enough to meet the disabled person's ‘eligible’ needs and pay for all the services as set out in the care and support plan. The personal budget can be used by the disabled adult in three different ways: by services being provided directly by the local authority (such as the local authority providing

a placement at a day centre) or commissioned through an organisation like a charity, or by the provision of direct payments, or by a combination of these methods.

“Direct payments” are cash payments given directly to disabled adults (or their families where the adult lacks the capacity to manage their money themselves) so that they can choose what services to buy and organise their own support. This is an alternative to services being commissioned or provided directly by the local authority. The idea is that disabled adults and their families will have more choice and control over their own care by using direct payments. If the disabled adult requires carers, this means employing carers directly. Disabled adults and their families can get help managing their direct payments by using local direct payment support services (DPSS), which are usually provided by local authorities and by user-led organisations.

Note – If your family member has health needs as well they may meet the criteria to be fully funded by health, or to be jointly funded by health and social care. See below for more information on funding from health authorities.

3. Regulation 2(3) of the Care and Support (Eligibility Criteria) Regulations 2014

4. Paragraph 10.5 of the Care and Support Statutory Guidance 2014

If you are not happy with the contents of a care and support plan provided by the local authority (for example, you do not think it will meet your relative's needs) then you can seek advice from a solicitor.

If a complaint about a care and support plan or about the amount of funding the local authority is willing to provide to a disabled person does not resolve the issue, then families may wish to complain to the Local Government Ombudsman and/or get legal advice from a specialist solicitor. Again, disputes about care and support planning and the duties to provide funding or services to disabled adults can be challenged by way of an application for judicial review, but note that proceedings need to be issued promptly and in any event within 3 months of the date of the decision. A solicitor will be able to advise whether judicial review proceedings are appropriate, or if the matter is more suitable for a complaint.

6. What if my family member needs support from health services as well as social care from the local authority?

If, during the assessment process (described above), it appears to social services that your relative has a health need or a housing need, it has a duty in law to notify the relevant housing or National Health Service (NHS) authority

The NHS⁵ or housing authority should then respond by conducting its own assessment of your relative's health/housing needs. In any event, there is a duty on local authorities, the NHS, and other agencies "to co-operate with one another in order to secure and advance the health and welfare of people in England and Wales" under the NHS Act 2006 and there is a similar requirement under the Care Act.

People with more complex needs may be eligible for NHS continuing care (sometimes called fully-funded NHS care). In that situation, the NHS is responsible for meeting both the health needs and the social care needs for the disabled person. Your family member will be eligible for continuing healthcare if he/she has a "primary health need". This is likely to be the case if your relative has complex medical needs. For example, if she/he has complex medication needs, feeding tubes, complex psychological or behavioural difficulties that require specialist input, complex continence needs, etc., they may be eligible for continuing healthcare.

A major advantage to receiving NHS funded care is that it is free. This is as opposed to social care from local authorities, who have the right to charge service users for services depending on the person's financial circumstances.

A continuing healthcare assessment will usually be carried out by a nurse assessor by using a "Decision Support Tool". This tool enables the nurse to consider a number of "domains" of medical needs, including behaviour, cognition, psychological/emotional needs, communication, mobility, nutrition, continence, skin and tissue viability, breathing, drug therapies, altered states of consciousness and other significant care needs.

In each of the domains the medical need is assessed as being 'Priority', 'Severe', 'High', 'Moderate', 'Low' or 'Nil'. If there is one priority need or two or more severe needs, there is a clear recommendation that the disabled adult is eligible for continuing healthcare. If there is one severe need together with needs in a number of areas, or a number of domains overall with high and/or moderate needs, this may also indicate that the disabled adult is eligible for continuing healthcare.

Just like for local authorities, the NHS is under a duty to meet the needs of disabled adults and their carers identified as part of the continuing healthcare assessment.

5. Clinical Commissioning Groups (CCGs) are the health bodies with responsibility for planning and buying health services for people in their local community. NHS England funds CCGs to commission services for their communities and has a responsibility to ensure that they do this effectively. Some specialist services remain the responsibility of NHS England, to be commissioned centrally, including some specialist hospital provision like adult secure mental health services.

In the same way you can organise your own community care services with the local authority using a “personal budget”, you can agree the best way to meet your health needs with the NHS using a “personal health budget”. Direct payments for health care are available in a similar way to social care.⁶

Whether your family member meets the criteria for a package of care funded fully by health (CHC), by the local authority, or where the local authority and NHS work together to provide a joint package of care – your family member should be able to get their needs met in a personalised way.

If your family member has a continuing healthcare assessment but are unhappy with the outcome (for example, it says that he/she is not eligible and you think he/she should be) you can appeal the decision by using our template letter: www.irwinmitchell.com/medialibrary/IM%20COM/Home/Documents/Continuing%20Healthcare%20Appeal.docx

As with social care, families may wish to consult specialist solicitors if they are not happy with the way in which their healthcare needs have been assessed or the care that is proposed.

7. Does my family member have a right to a “behaviour support plan”?

A behaviour support plan is a step-by-step guide to reducing challenging behaviour and improving the person’s quality of life. If your relative has behaviours which services may find challenging, he/she may benefit from a behaviour support plan. As above, it may require specialist input from a psychologist or psychiatrist to develop this support plan, which will require involvement by the NHS. See above for more information about how to request input from specialists. Again, any request for a behaviour support plan cannot be unreasonably refused.

8. Is my family member entitled to a “personal budget”?

Yes. The amount of a personal budget from the local authority is “the cost to the local authority of meeting those of the adult’s needs which it is required or decides to meet”. This language is taken from the new Care Act. As such a personal budget must be sufficient for the disabled person or family to buy the services required to meet assessed eligible needs. See above for more information about care and support plans and personal budgets.

If the person is fully funded by health (CHC)

they are also entitled to a personal budget and to receive direct payments (either directly or via their family or other third party if they don’t have capacity to make decisions about how to spend it), in a way that is similar to social care.

9. I am happy with the care and support plan but it is not being followed. What can I do?

If your care and support plan is not being followed then the local authority is failing to meet the needs of your family member. This is unlawful, and you can make a formal complaint to the local authority and/or approach a community care solicitor for advice about how to challenge the local authority’s unlawful behaviour.

10. If I am not happy with the care and support plan, how do I challenge it?

The local authority should involve you or your relative throughout the assessment process. If somebody has significant difficulty with understanding or engaging with the assessment process, an advocate should be appointed for them.

6. Regulation 32B(4) of the National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012 states “Where a request is made by or on behalf of an eligible person for a personal health budget, a relevant body must grant that request, save to the extent that it is not appropriate to secure provision of all or any part of the relevant health service by that means in the circumstances of the eligible person’s case.”

As the Care Act provides that the assessment and care and support plan must be based around the wellbeing and needs of the individual, you or your family member will be able to provide your views throughout this process including on the proposed final care and support plan.

The local authority should therefore provide you with a draft care and support plan before it is finalised. This is because local authorities should agree the eligible needs and outcomes determined during the assessment process and keep a written record of this. If you are still not happy with the draft plan, then the local authority should take all reasonable steps to reach an agreement with the disabled person about the kind of support to be provided.

When you are provided with the draft care and support plan this is an opportunity for you to consider the contents and suggest amendments. Remember that the care and support plan should be detailed, setting out the what, how, when, and who of service provision. If any part of it does not reflect you or your relative's view about what he/she needs, then explain this to the social worker. When you sign the care and support plan, you are normally agreeing to the contents.

Sometimes families feel pressured to accept a care and support plan that they do not agree with. If you are not happy with the care and support plan, bring this to the attention of the social worker and explain why. If this does not resolve the problem, then consider making a formal complaint. More information about how to make a complaint is below. Depending upon the nature of the disagreement, the impact it is having on your relative and the urgency of the matter, you may want to approach a specialist solicitor who can challenge the lawfulness of a care and support plan. More information about judicial review and funding a case is also set out below.

At the time of writing this factsheet, new proposals have been put forward for an independent review process in relation to the care assessment and care and support planning process. These proposals are currently subject to consultation, however from April 2016 it is likely that there will be a new formal complaints process which allows for a staged response to complaints regarding the care assessments and care and support plans, with the right to seek an independent review of the decisions that have been made. This would not affect your right to seek legal advice.

11. Is my family member entitled to advocacy?

Under the Care Act 2014 local authorities have a duty to provide an independent advocate in certain situations. If your relative would experience substantial difficulty in participating in their social care assessment or review and / or the preparation of their care and support plan, then the local authority must provide an advocate.

There is no duty to do so if the local authority is satisfied that there is some other person who is an appropriate representative, such as a family member (provided that person is not engaged in providing professional care for your relative). The exceptions to this are where the local authority is taking a decision about whether the person should move to an NHS funded placement in a hospital for 4 weeks or more, or a care home for 8 weeks or more, or where there is a disagreement between the local authority and the person's "appropriate representative" and it is agreed that an advocate should be appointed.

There is already a right to advocacy in certain situations – for example, under the Mental Capacity Act 2005 if a person lacks capacity and is unbefriended then an Independent Mental Capacity Advocate (IMCA) must be

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When needs are not met

instructed in relation to certain key decisions (serious medical treatment or changes in accommodation). If someone is detained under the Mental Health Act then they are entitled to an Independent Mental Health Advocate (IMHA).

Local support and availability

12. There are no support services in my local area to help when there is a crisis. What can I do about this?

Sometimes, there are insufficient support services in a local area to step in when there is a crisis. This can result in an admission or readmission to a hospital or other residential settings when this could otherwise be avoided.

Local authorities will usually have out of hours social workers on duty if a crisis occurs during evenings or weekends. You can find out the telephone number to call in a crisis on your local authority's adult services website.

The responsibility to provide adequate local services lies with local authorities and with the NHS. There are a number of duties these public bodies have to provide services to meet the needs of people in the local area under various statutes, including the 2006 NHS Act. These are broad duties, and whether you can challenge a failure to provide a specific crisis service in your local area depends a great deal on the facts. If the failure can be challenged, then it will be by judicial review, and a community care solicitor should be able to provide advice, often funded by legal aid, about whether there are merits to the case.

13. The right support services are available locally, but the local authority or NHS is reluctant to provide funding to access them. What can I do about this?

Sometimes families may be able to identify what they believe is an appropriate placement for their loved one in the local area, or a bespoke care package, but the local authority

or NHS is reluctant to fund it.

Under section 18 of the Care Act, local authorities have a duty to provide services to meet all your relative's eligible needs, provided that they are ordinarily resident in the local authority's area. The local authority should also take into consideration the preferences of your family member and his/her family carers. However, local authorities are entitled to deliver the service in the most cost-efficient way possible so long as the need is still being met. Therefore, if there are two options available, both of which will meet your relative's needs, and one is cheaper than the other, the local authority can usually elect to provide the cheaper option. An important exception to this would be when the cheaper option would be inconsistent with the person's human rights – you may need advice on this from a specialist lawyer.

However, if you have identified a local service that is right for your relative, and their needs

are not being met by the cheaper service that the local authority is willing to provide, then it is likely that you can challenge this.

It is also important to consider the 'wellbeing' principle in the section 1 of the Care Act. Local authorities are under a duty to promote an individual's well-being, which includes a consideration of their personal dignity, health and wellbeing, their access to the community and maintaining relationships. This duty could be relied upon to ensure your family member can access the support that is right for them.

If a local authority refuses to provide a service that you think is more suitable to your relative's needs, then consider making a formal complaint. Also, consider contacting a community care solicitor, who will advise you about whether you can challenge the local authority's decision in court.

Often the NHS will have its own services which are available to all, subject to an agreement that the service is necessary to meet the assessed need. If your relative's needs are met by the NHS and you think that funding is preventing the service from being made available, you may want to approach a solicitor.

Exclusion

14. Can my family member be excluded from a service because his/her behaviour is too challenging?

Your family member has the right to access healthcare and support. If she/he exhibits challenging behaviour, then he/she may require specialist support from a behaviour support team. This may involve a specific focus on how to manage challenging behaviour to promote access to the services your family member prefers.

If he/she is attending a particular service (for example, a day service) and the staff cannot cope with his/her challenging behaviour, consider raising your concerns with social services at an early stage. It may be that your relative requires more support than he/she is getting in order to continue accessing that service, and they are under a duty in accordance with the Equality Act 2010 to make reasonable adjustments to meet your family member's needs. You can seek independent advice from a solicitor if you feel that reasonable adjustments are not being made. Ultimately however, if an individual's behaviour is considered to be too challenging, possibly for example because they need restraining but staff are not appropriately trained, then they could be asked not to return. The local

authority or NHS would still however be under an obligation to meet their needs by finding another placement or even setting up a bespoke care and support plan if there are no other services available to them.

Changes to support

15. If my family member is not getting enough support, how do I challenge this?

If your relative is not getting any support, or not getting enough support, then notify the local authority as soon as possible so that they can have a needs assessment, and a care and support plan can then be put in place.

If your relative is getting some support, but not enough, then you probably need to request a reassessment from the local authority. The only situation where a reassessment would not be required is where the current assessment accurately identifies your relative's needs but the local authority is failing to provide services to meet them – in which case the problem is with the care and support plan.

You can request a reassessment in writing to the social worker by explaining why the support is not enough (for example, have your relative's needs increased?). Just as above, when requesting a first assessment, a reassessment or review should be conducted within a

reasonable time. If it is not, then consider making a formal complaint and seek advice from a community care solicitor.

If your relative's needs are urgent and/or the lack of support is having a significant impact on your relative, you may want to approach a solicitor. Your solicitor can request the local authority provides interim support pending a review if it is urgently required.

16. How can I get my family member extra support at home?

If your family member is not getting the right level of support at home, then contact the local authority and request a reassessment. It may be that social services will make a referral to the NHS if your relative also has health needs that are not being met at home. See above for information about requesting a needs assessment and about how the NHS and local authorities should work together.

17. How can I change the support my family member is getting if his/her needs have changed since the last assessment?

If your family member's needs have changed since his/her last assessment, then request a reassessment from the local authority. You can do so in writing or by telephone to the

social worker or adult social care department, explaining how your relative's needs have changed. Just as above when requesting a first assessment, a review should be conducted within a reasonable and appropriate timescale. If it is not, then consider making a formal complaint and/or seek advice from a community care solicitor.

If your relative's needs are urgent, approach a solicitor as soon as possible. Your solicitor can request the local authority provides interim support pending a review if it is urgently required.

18. My family member is nearing 18. What rights does she/he have in the transition from being a child to being an adult?

Planning for the transition period between childhood and adulthood should start at 14 years old for children who have a statement of special educational needs⁷ (these are now being replaced with Education, Health and Care Plans). At this point, social services should contact your family member to carry out an assessment. If your family member is statemented and has reached 14 but has not been contacted by the local authority, write to social services and explain that your family member requires an assessment for his/her transition period.

Under section 58 of the Care Act, local authorities have a duty to conduct an assessment of a child's needs for care and support where it appears to the local authority that a child is likely to have needs for care and support after becoming 18, where it would be of significant benefit to the child, and where there is consent to an assessment.

The purpose of the assessment is to consider whether the child has needs for care and support now or after reaching the age of 18, and to find out what those needs are. The assessment must have regard to the wishes and preferences of the child, the outcomes that are sought, and the severity and overall extent of needs.

Once the child's needs assessment has been completed, under section 59 of the Care Act the local authority will need to provide an indication as to which of the child's needs are likely to meet the eligibility criteria after the age of 18, and advice and information about what can be done in order to meet or reduce the needs now and what can be done to delay or prevent further or more extensive needs developing. When the child reaches the age of 18 the local authority may decide to treat the child's

7. Under section 5 of the Disabled Persons (Services, Consultation and Representation) Act 1986

needs assessment as a full needs assessment under the Care Act in order to ensure a smooth transition without any delays or gaps in provision.

If the local authority decides not to treat the child's needs assessment as a full needs assessment, local authorities have a power to continue to provide the services currently being provided after the child's 18th birthday.

As stated above, local authorities have a duty to conduct a carer's assessment on appearance of need, consider whether the carer's needs are eligible, and provide a carer's support plan. A similar duty in respect of carers of disabled children, who are likely to have needs once the child reaches 18, is contained in section 60 of the Care Act.

Challenging decisions about services

19. My family member's current placement is not right for them (eg. there are too many people living there and the staff don't have the right skills). It makes his/her behaviour worse. How can I get him/her moved?

You can start by alerting the local authority that your family member's placement is not suitable

for their needs and request a reassessment and/or that it is in their best interests to be moved. During the reassessment process, explain to the social worker why your family member is not getting the care they need and the potential consequences if they remain where they are. Be sure to request appropriate experts are involved in the reassessment process and ensure it captures all the necessary detail. If you feel the situation is reaching a crisis point, explain the urgency to the local authority and approach a community care solicitor if the local authority is not acting to address the situation.

If the dispute is about what is in their best interests, and agreement cannot be reached, then it may be necessary for the matter to be considered by the Court of Protection.

20. If the public authority says that my family member can't receive care at home, how can I challenge this?

Sometimes, the NHS body or the local authority responsible for your family member's care may say that his/her needs cannot be met at home. This is often the case where his/her needs are very complex or he/she exhibits very challenging behaviour. If your family member's preference, and/or your preference, is for him/her to remain at home and receive a package of

care in the home, then this should be taken into consideration by the decision maker.⁸

A bespoke care package can sometimes be set up to ensure that their needs are met at home. The decision maker in this case may be the local authority or the CCG, and the individual's rights to a private and family life under the Human Rights Act 1998 will need to be considered. However, an authority can take into account the cost of the bespoke placement compared to residential care when considering how to meet the person's needs. Any decision to refuse to set up a bespoke plan could be challenged by judicial review, and specialist advice should be sought from a community care solicitor.

Even if the plan is to move your family member into a residential placement or into hospital, it should be as close as possible to home, in order for your family member to remain close to family and friends and to enable them to remain a part of their local community.⁹ He/she should only be moved out of area if it is particularly suitable to meet his/her needs. See below for more on what to do if the local authority or NHS want to move someone a long way from home.

8. This is because choice and control are supposed to be at the heart of the community care and support planning process. Within the Regulations and Guidance accompanying the Care Act 2014, there are numerous references to the need to put choice and control in the hands of disabled people.

9. This has been a policy objective of the Government since 2011, see the Department of Health's policy "Valuing People: A new Strategy for Learning Disability for the 21st Century" at para 6.30

If he/she lacks capacity to decide where they live, it is likely that a best interests decision will need to be taken under the Mental Capacity Act 2005. This should be done in consultation with you and you may be able to challenge the ultimate decision in the Court of Protection and/or in judicial review proceedings. There is more information below about judicial review and about the Court of Protection.

These cases are often very complex and whether you can challenge the decision will depend on the facts, so it would be prudent to contact a community care lawyer as soon as possible if you are notified that your relative cannot be cared for at home for advice.

21. The public authority wants to send my family member to a placement too far from home. How can I challenge this?

The local authority must provide services that meet your family member's eligible needs. Sometimes, local authorities and NHS bodies argue that the only placement that will meet his/her needs is far from home. This can be very difficult for families who want to be able to visit regularly, and for your family member who relies on support from the family.

It may be possible to challenge the decision to move your family member to a placement

far from home if it will not meet his/her needs or if it is not the most appropriate placement for them. It may also be arguable that moving your family member far from home breaches his/her right to a private and family life under the Human Rights Act 1998. This may be the case if, for example, a bespoke community placement could be created to meet your family member's needs. Any such challenge will be made by judicial review or possibly in the Court of Protection (see below for more information) and expert legal advice will be required. Legal aid is likely to be available to obtain this advice.

A failure to consider the person's family relationships, their own wishes and feelings, and their physical and mental health and well-being, may also breach section 1 of the Care Act 2014, which requires a local authority to promote an individual's well being.

It may also be possible to challenge the CCG's failure to commission adequate services in the local area. The NHS Acts require adequate provision of services to meet patients' health needs in local areas. Furthermore section 5 of the Care Act places local authorities under a duty to promote the efficient and effective operation of a market in care services. However, this is a complex area of law and you are likely to require expert legal advice about whether

there are sufficient merits to bring a legal challenge such as this.

22. My family member's home has been adapted, but I am not happy with the results. What can I do?

If you are unhappy with the quality of the adaptations to your family member's home, then the first step is to make a formal complaint. Make sure that you explain why the adaptations are inadequate and the effect it has on your family member.

If the formal complaint does not resolve the matter, you want to approach the local government ombudsman or approach a specialist solicitor for advice about how to take it further. It may be that you can challenge the failure to provide suitable adaptations if they fail to conform to the recommendations set out in the assessment, or if they will not meet your family member's needs.

Decision Making (the Mental Capacity Act)

23. I am concerned that I am being shut out of decisions being made about my family member's care. What rights do I have to be involved?

Families frequently report concerns that decisions have been taken about the welfare of their relative, without them being properly consulted.

If an adult lacks the mental capacity to make a particular decision (for example about where they are going to live), then any decision made on his/her behalf must be made in their best interests and in accordance with the Mental Capacity Act 2005. The kinds of decisions that might be made on behalf of a person who lacks capacity may be about where he/she lives, what care he/she receives, what contact he/she has with others, and what medical treatment he/she receives. All professionals, including social workers and doctors and nurses, must consult with family members before taking a decision on behalf of a person who lacks capacity if it is practicable and appropriate to do so. This is a legal duty under the Mental Capacity Act.

The Care Act also imposes new duties to consider where an individual may have 'substantial difficulty' in engaging in the assessment and care-planning process. Where this is the case, then an appropriate individual will need to be consulted about their needs (for example a family member), or where there is no appropriate individual, an independent advocate would need to be appointed.

If you are concerned that decisions have already been taken and you were not consulted, then you can use our template letter to register your concern and request a "best interests meeting": www.irwinmitchell.com/medialibrary/IM%20COM/Home/Activities/Documents/Template-letter-2.doc

If you are concerned that decisions may be taken by professionals without consulting you in the future, you can use our template letter to explain your right to be consulted: www.irwinmitchell.com/medialibrary/IM%20COM/Home/Activities/Documents/Template-letter-1.doc

If you wish to gain legal authority to make decisions about money, property and/or welfare on behalf of a family member who lacks capacity, you can apply to the Court of Protection to become a Deputy. However, you do not need to be a Deputy in order to be

consulted by professionals before decisions are made on your relative's behalf. The Mental Capacity Act is clear that professionals must consult with you anyway.

You may want to consider applying to become a personal welfare deputy if there is a series of one-off decisions to be made, to break through an impasse (for example, between "warring" family members) or to save time and expense of regularly returning to the Court of Protection to authorise decisions.

It is however important to note that the Court is reluctant to appoint personal welfare deputies unless there is a particular reason why this is required in any given case. You can find out more about becoming a Deputy here:

www.challengingbehaviour.org.uk/learning-disability-files/15---Making-Decisions-web.pdf

If your relative has capacity to make the relevant decisions for him/herself, then you do not have a right to be consulted by professionals. It will be a matter for your relative to make the decision. He/she can involve you in making any decision as much or as little as he/she wishes to. His/her wishes must be respected by the professionals.

24. My family member is under the MHA – do I have a right to be involved in decisions about their care and treatment?

This very much depends upon what the decision is, whether your family member has the capacity to make the decision themselves, what their views are on the family member's involvement, and whether they have capacity to consent to disclosure. In the first instance you should ask to be involved, and if refused ask for clear reasons why. If you are not satisfied with the answer, you may well need independent legal advice.

Meeting the challenge

The Mental Health Act

Detention under the MHA

25. The public authority wants to detain my family member in an inpatient unit. How can I challenge this?

If a public authority wishes to detain your relative, but has not already done so, you may be able to prevent it by seeking legal advice immediately.

It may be the case that your relative was admitted voluntarily to hospital but the doctors indicate that they want to prevent your relative from leaving, or it may be that the police or doctors believe your relative should be taken to hospital to be detained. Either way, the following principles apply.

There are two ways your relative could be lawfully detained in an inpatient unit: under the Mental Health Act 1983 (“MHA”) or under the Mental Capacity Act 2005 (“MCA”).

The Mental Health Act

If your family member suffers from a “mental disorder” (see below for more on what this means), then Approved Mental Health Professionals (AMHPs)¹⁰ have the power under the MHA to “section” (or detain) your relative if they consider it necessary and in the interests of his/her own safety or the safety of others. Usually, two doctors must examine and assess your relative and recommend that the criteria under the Act are met before he/she is sectioned.

A person, including a person with a learning disability, can be detained under section 2 of the MHA in order to carry out an assessment if:

- a. He/she is suffering from “a mental disorder of a nature or degree that warrants detention in hospital for assessment” (or assessment followed by medical treatment) for at least a limited period; and

- b. He/she ought to be detained in the interests of his/her own health or safety, or with a view to the protection of others.

A person, including a person with a learning disability, can be detained under section 3 of the MHA in order to receive treatment if:

- a. He/she is suffering from a “mental disorder of a nature or degree” that makes it appropriate for them to receive medical treatment in hospital; and
- b. It is necessary for his/her own health or safety, or for the protection of others, that he/she receives such treatment and it cannot be provided unless he/she is detained under this section; and
- c. Appropriate medical treatment is available for him/her.

10. The Mental Health Act gives AMHPs the power to make an application to admit you to hospital under a section of the Act if they consider it necessary and the best way of ensuring you receive the right care and treatment. An AMPH can be a social worker, nurse, occupational therapist or psychologist who has been approved by a local authority.

'Mental disorder' is defined in the Mental Health Act as "any disorder or disability of mind". This includes any mental health problem (e.g. depression or schizophrenia), as well as autistic spectrum disorders (including Asperger's syndrome) and learning disabilities.

However, someone with a learning disability and no other form of mental disorder may not be detained for treatment unless their learning disability is accompanied by 'abnormally aggressive or seriously irresponsible conduct' on their part.

The AMHP must consult the person's nearest relative before sectioning them, if they are being admitted under section 2 or section 3. However, the person's nearest relative cannot prevent them from being admitted under section 2. They can object to detention under section 3 going ahead, in which case the AMHP must apply to the County Court for an order "displacing" the nearest relative or taking their powers away from them.

The Mental Health Code of Practice states that when deciding whether it is necessary to detain patients, that doctors and AMHPs must always consider the alternative ways of providing the treatment or care they need and whether there are less restrictive alternatives to detention under the Act. This includes through

management in the community. The Code of practice also states that consideration should be given to:

- the patient's wishes and view of their own needs
- the patient's age and physical health
- any past wishes or feelings expressed by the patient
- the patient's cultural background
- the patient's social and family circumstances
- the impact that any future deterioration or lack of improvement in the patient's condition would have on their children, other relatives or carers, especially those living with the patient, including an assessment of their ability and willingness to cope, and
- the effect on the patient, and those close to the patient, of a decision to admit or not to admit under the Act.

The sections above (sections 2 for assessment and 3 for treatment)are to be used in most circumstances, but if the situation is urgent then your relative can be detained under section 4 for an emergency admission to hospital for up to 72 hours on the recommendation of one doctor.

If you do not believe the criteria set out above applies to your relative, then seek assistance from a mental health lawyer as soon as possible for advice about whether you can prevent your relative from being sectioned in hospital.

Under the Act people can also be 'sectioned' and detained in an inpatient setting via the Court or prison system. The rules around the detention of someone in these situations are different to those outlined above. For example, the rules around the role of the Nearest Relative are different. You can find out more on Mind's website here:

www.mind.org.uk/information-support/legal-rights/nearest-relative/nearest-relatives-rights/

The Mental Capacity Act

If the MHA does not apply to your family member's situation, but they lack mental capacity in relation to their own care and treatment, then they may be deprived of their liberty under the MCA. It would have to be in their best interests to do this.

A set procedure must be followed in order for a deprivation of liberty to be lawful. It is the responsibility of the 'supervisory body' (e.g. the Local Authority), to ensure the procedure is followed. Firstly, a mental capacity assessment

must be carried out to determine whether your family member lacks capacity to decide whether to be admitted to hospital. If they have capacity to make this decision, then your family member cannot be forced to go into hospital unless the criteria under the MHA are met (see above).

If your family member does not have capacity to decide about admission, then a mental health assessment must be carried out to check whether they should actually be detained under the MHA (above). A best interests assessment must also be carried out to ensure that it is in your family member's best interests to be deprived of their liberty. It may be in their best interests if it is necessary in order to prevent them from coming to harm and it is a proportionate response to the likelihood of them suffering harm and the seriousness of that harm. If it is, then the Local Authority will grant an urgent or standard authorisation of his/her deprivation of liberty, subject to a number of other assessments being carried out (for example in relation to the person's age).

If you believe your family member has capacity, or you do not believe it is in their best interests to be deprived of their liberty in hospital, then contact a community care solicitor as soon as possible for advice about whether you can prevent your relative from being detained in hospital.

26. My family member is being detained in an inpatient unit. How long can they be detained for and should their case be regularly reviewed?

If your family member is being detained under the Mental Health Act 1983¹¹, their detention time and any renewal of a period of detention depends on the type of section they are being detained under:

- Under section 2 your family member can only be detained for up to 28 days, although they may not stay for this long. At this point your family member will either be discharged or transferred onto section 3 for treatment;
- Under section 3, your family member can be detained for up to 6 months, although they could be discharged before this time is up. Detention under section 3 can be renewed for a further 6 months. After that, detention can be renewed for further periods of one year at a time.

See above for more information about how to challenge your family member's detention as an inpatient under the MHA.

27. My family member is being detained in an inpatient unit. What rights to I have to visit them? If visits are being restricted, how can I challenge this?

Generally, restrictions on visiting rights for families must be proportionate and in the best interests of patients, including the relative of the family in question. This is because families' rights to family life under Article 8 of the European Convention on Human Rights are clearly engaged by any restrictions on visits to detained patients. To say Article 8 is "engaged" means that there will be an interference with the family member and patient's Article 8 rights if visits are restricted; however sometimes such restrictions can be justified if, for example, there is a good reason for it and on balance it is proportionate.

Under the Code of Practice for the Mental Health Act 1983, all patients in hospital under the MHA have the right to be visited by anyone they want to see. Hospitals are encouraged to make visits as comfortable and easy as possible for both the patient and the visitor. Having flexible visiting times and access to pleasant surroundings will contribute to this.

Hospital managers can only restrict or prevent certain visitors in some circumstances. They can only do so on clinical grounds (e.g. the clinician believes visits will be detrimental to the safety or wellbeing of the patient) or security grounds (e.g. the behaviour of the visitor is very disruptive).

11. <https://www.gov.uk/government/publications/code-of-practice-mental-health-act-1983>

Since the decision to prohibit a person (who the patient wants to see) from visiting is a serious interference with the patient's human rights, other ways of dealing with the problem should be considered first.

If you are unhappy with any restrictions on visiting your family member in hospital, first ask to see the hospital's policy regarding visits. This will provide you with more information. You can also make a formal complaint to the clinician in charge of your family member's care, and approach a mental health solicitor if this does not resolve the problem.

If your family member is being deprived of his/her liberty under the Mental Capacity Act 2005 in order to receive treatment in hospital, then the hospital's normal policy regarding visitors will apply. If your family member has capacity in relation to contact with other people, then he/she can accept visits from anyone that he/she wants to see. If your family member lacks capacity to make decisions in relation to contact then the usual process under the Mental Capacity Act should be followed, which means initially all the relevant parties should seek to reach a consensus on what is in his/her best interests. If there is a dispute between members of the family and/or professionals involved in his/her care about whether it is in your family member's best interests to see certain people, then you may want to seek

the assistance of a community care lawyer for advice about how to resolve this.

28. My relative is being detained in an inpatient unit. Who has overall responsibility for his/her treatment?

A number of professionals are likely to be involved in your relative's treatment in hospital, but under the MHA it is the "Responsible Clinician" who has the overall responsibility for a patient. On admission, your relative will have been assigned a Responsible Clinician, who may be a doctor, psychiatrist, psychologist or similar. If you have any queries or concerns about the overall treatment your relative is receiving, the first person you should contact is the Responsible Clinician.

29. What are my family member's rights in relation to medical treatment and care conditions in the unit? If I am not happy with his/her medical treatment or care conditions, how can I challenge this?

If you are not happy with your family member's medical treatment or care conditions (for example, overuse of medication, lack of positive behaviour support, the use of seclusion, the use of restraints, a lack of meaningful activities, lack of access to fresh air, not meeting physical health needs etc.), then first consider raising

the matter with the clinicians with responsibility for his/her care. If this does not resolve the matter, depending upon the urgency of the situation, consider making a formal complaint to the relevant NHS body, for example the Clinical Commissioning Group or hospital trust. See below for more information about what do to if you are concerned that your relative is receiving a poor standard of care.

If a formal complaint does not resolve the matter, or it is very urgent, then how to challenge this depends on whether your relative has capacity.

If your relative has capacity to make the decision

If your relative has capacity to make decisions regarding his/her own medical treatment, then they are entitled to refuse that treatment. If they want treatment that is not being provided, a decision not to provide that treatment can be challenged by judicial review although this is not straightforward and specialist legal advice should be sought.

However, it is important to note that if your relative is detained under the MHA they can be treated in the first three months of their detention (under Sections 2, 3 and 37) without their consent (although some treatment, even in the first three months, always requires consent and/or a second opinion doctor). After

3 months if your relative doesn't consent to treatment a second opinion doctor (SOAD) must be consulted and your relative can be given medication without their consent if the SOAD agrees with the responsible clinician. Your relative cannot make an advance directive to exclude treatment whilst detained under the Mental Health Act.

If you or your relative are not happy with the treatment the responsible clinician wants to give your relative (and which the SOAD has agreed to), see 'Ways to raise concerns and challenge decisions' section (Pg 33).

Note: Treatment for physical problems (i.e. not for a mental disorder) cannot be given without consent unless your relative also lacks capacity and it is agreed to be in their best interests.

If your relative does not have capacity to make the decision

If your relative does not have capacity to make decisions regarding his/her own medical treatment, then a best interests decision will be taken. This should include parents/ family members where appropriate, and ultimately if agreement cannot be reached an application can be made to the Court of Protection to determine whether the decision is in his/her best interests.

30. My family member is being detained in an inpatient unit. I am concerned that

the professionals involved in decisions about whether they remain detained, are not independent. How can I challenge this?

Under the Mental Health (Conflict of Interest) (England) Regulations 2008, a professional cannot apply to detain a patient where there is a conflict of interest. Under the Code of Practice for the Mental Health Act 1984, it explains that conflicts of interest may arise where there is a relationship between the professionals involved, the doctors, the hospital where your relative is being detained, or to his/her nearest relative. This could for example be a financial or personal relationship.

If you are concerned that there may be a conflict of interest, which means that the professionals involved in your family member's detention are not suitably independent, then raise your concerns with the hospital managers and the clinicians with responsibility for your family member's care. If this does not resolve the matter, then approach a mental health solicitor for further advice.

31. My family member is being detained in an inpatient unit. Does he/she have a right to an IMHA / IMCA?

Whether your family member has a legal right to an advocate depends on the circumstances of their detention.

If they are being detained under the Mental Health Act 1983 (sections 2 or 3 or any criminal section) then they are entitled to an Independent Mental Health Advocate (IMHA).

If your family member is being deprived of their liberty of their liberty under the Mental Capacity Act 2005, an Independent Mental Capacity Advocate (IMCA) can be appointed if:

- The person is aged 16 or over;
- A decision needs to be made about either a long-term change in accommodation or serious medical treatment;
- The person lacks capacity to make that decision; and
- There is no one independent of services, such as a family member or friend, willing and able to represent them or be consulted in the process of working out their best interests.

Under the Mental Capacity Act, an IMCA must be instructed if the decision relates to:

- Providing, withholding or stopping serious medical treatment;
- Moving a person into long-term care in a hospital or care home; or
- Moving the person to a different hospital or care home.

32. My family member is being detained in an inpatient unit. Does he/she have a right to a lawyer?

Yes. If your family member is being detained under the Mental Health Act 1983, your relative can request the assistance of a lawyer at any time. If they lack capacity to instruct a lawyer or to ask for one, then normally the Mental Health Act Administrator at the hospital will inform the Mental Health Tribunal office, who will appoint a lawyer on your family member's behalf from the Law Society's Accreditation panel. The lawyer will have a duty to act in your relative's best interests.

If your family member is being deprived of their liberty under the Mental Capacity Act 2005 and an application is made to the Court of Protection (by the local authority, or by a family member with the assistance of a solicitor), then your family member should have the assistance of a solicitor. If the person who lacks capacity does not already have a solicitor when an application is made to the Court of Protection, then the court will invite the "Official Solicitor" to act for them.

Legal aid is usually available for these types of cases, and in some circumstances that can be regardless of your family member's capital and income. It may be appropriate for you

to act as his/her "litigation friend", meaning that you will provide instructions to a solicitor on behalf of your family member. Otherwise, the court will refer the matter to the Official Solicitor. The role of the Official Solicitor is to act as a "litigation friend" on behalf of your family member if there is no family member or other person who is able to do so. The Official Solicitor will, in turn, instruct a solicitor to represent your family member in the Court of Protection proceedings. If you or the Official Solicitor is acting as litigation friend, there is a duty to act in your family member's best interests and to ensure that the court is aware of their wishes and feelings.

Meeting the challenge

Discharge and planning community support

33. My family member is being detained in an inpatient unit. How can I get them out?

The Mental Health Act

Under the Mental Health Act, there are different ways that someone can ask to be discharged. This will depend on which section of the Mental Health Act your family member is being detained under.

The Mental Health Act makes it a requirement in law for the hospital staff to provide the person being detained with information about their detention, including the different ways in which they can be discharged. As noted above, these are different depending on which section your family member has been detained under but include some or all of the following:

- At any time, your family member can ask his/her Responsible Clinician (the clinician with overall responsibility for the

person's care and treatment while you are under the Mental Health Act – often a psychiatrist) to consider discharge. At any time, your family member can ask the Mental Health Act Administrator at the hospital to convene a Hospital Manager's hearing to consider discharge

- The nearest relative can discharge your family member (sections 2 and 3 only) by giving the hospital managers 72 hours' notice in writing. The Responsible Clinician, however, can issue a barring certificate.
- Your family member can make an application to the Mental Health Tribunal for a discharge. There are different rules (see below) about when applications can be made and how often.

The Mental Health Tribunal is an independent body. The hearing will take place at the hospital where your family member is being detained. Your family member can apply to the Mental

Health Tribunal for a discharge at the following times:

- If your family member is detained under section 2, they can apply to the tribunal within 14 days; or
- If your family member is detained under section 3, they can apply once at any time within the first six months of their detention and, if the section 3 is renewed, you can appeal once during the second six months. You can then appeal once during each one year period.

In certain circumstances, a nearest relative can also apply to the Mental Health Tribunal for their family member to be discharged.

If your relative is detained under section 3 of the Mental Health Act and does not make any application to the Mental Health Tribunal, this will happen automatically at the following times:

- In the first 6 months of detention; and
- After that, every 3 years;
- Unless he/she is under 18, in which case it will automatically occur after one year.

The law in relation to all of the above options is very complex. It is important to seek the advice of a mental health lawyer as soon as possible, who will guide you and your relative through the process.

The Mental Capacity Act

You cannot be ‘detained’ under the Mental Capacity Act 2005, but an urgent or standard authorisation can be put in place to deprive your relative of his/her liberty under the Deprivation of Liberty Safeguards (“DoLS”) of the MCA (see above for more on this).

If this has happened, and you don’t think it is in your family member’s best interests, then you may want to seek legal advice from a community care lawyer as soon as possible. Legal aid is available to all people, regardless of their income/capital, to challenge DoLS authorisations. A lawyer can assist you by

appeal against your relative’s deprivation of liberty to the Court of Protection. Essentially, the Court of Protection will consider the deprivation of liberty and make a decision about whether it is in your relative’s best interests to be deprived of his/her liberty or released. For example, it may be that it was appropriate to authorise the deprivation of liberty when your relative was first admitted to hospital, but it is now in his/her best interests to be discharged.

34. My family member is currently an inpatient at hospital and I am concerned about what will happen when he/she is discharged. How can I have my concerns addressed?

Discharge planning should start as soon as your family member is admitted to hospital.¹² Throughout the discharge planning process, your family member, you, and your relative’s advocate should be involved and all of your views should be taken into account by the NHS, unless your family member does not want their family involved.

There may also be issues about whether your family member has the capacity (as set out in the Mental Capacity Act 2005) to make decisions around their future care and support needs after they are discharged. If you have any concerns about what will happen when

your family member is discharged, then raise these as soon possible with the doctors in charge of his/her treatment.

Remember that the NHS and the local authority must work together to ensure that all the care and support your relative will need on discharge is in place.¹³ This is to help prevent any delay to your relative’s discharge due to the right package of support not being in place at the right time. Whether the NHS or the local authority are responsible for your relative’s care after their discharge depends on both the legal basis for their admission to hospital (for example, what section of the Mental Health Act they have been detained under) and the nature and extent of their needs.

If you are concerned that the NHS has not contacted the local authority to make arrangements for your relative’s discharge, then raise this both with your relative’s doctors and with the local authority social services team. If you are concerned that your relative’s CCG has not been contacted about conducting a continuing healthcare assessment, then raise this both with your relative’s doctors and with the CCG.

12. Under the Department of Health Guidance, “Ready to Go? Planning the discharge and the transfer of patients from hospital and intermediate care”.

13. For example, under the Community Care Assessment Directions 2004 and the Community Care (Delayed Discharges etc) Act 2003.

Equally, if you are concerned that your family member is not ready for discharge and he/she should remain in hospital a while longer, raise your concerns with his/her doctors.

If you have tried to raise your concerns and you are still not having your concerns about discharge addressed, you can make a complaint and/or contact a specialist solicitor for advice about what steps to take next.

35. Discharge planning has still not started – is there anything I can do?

As stated above, discharge planning should start as soon as your family member is admitted to hospital.¹⁴ If this process has not begun yet and you would like to know what plans will be put in place for discharge, then speak first to your relative's doctors. It may be that some issue has caused a delay and so you should find out the reasons for this first. If you are not satisfied that the NHS is doing all it can to arrange for a timely discharge, you can make a complaint and/or contact a specialist solicitor for advice about what steps to take next.

36. My family member is in hospital and ready for discharge, but discharge keeps being delayed – is there anything I can do?

- a. What if it is because community services are not available?

As explained above, the NHS must give social services and/or the relevant health authority notice that your relative may need services on discharge. The local authority then has a duty to conduct a needs assessment and put the care arrangements in place and carry out a carer's assessment. A continuing healthcare assessment may also be needed. Following this, the NHS must give notice to social services of the day your relative will be discharged from hospital. This is to prevent any delay to discharging your relative once he/she is ready to return to the community.

If you are concerned that the local authority or health authority have not been notified by the NHS, or assessments are not completed within a reasonable time, then raise these concerns with the doctors in charge of your family member's care, and with social services. Consider making a formal complaint and contact a community care solicitor for advice about what steps to take next. Your family member may also have a damages claim for

unlawful detention if the delayed discharge resulted in them being detained for longer than was necessary.

- b. What if it is because there is a funding dispute between public authorities?

Sometimes disputes arise between public authorities about who should fund the support your family member requires. Very importantly however, even if there is a dispute of this kind, this should not create any delay in providing your relative with the support he/she needs.

The law is very clear that when there is a funding dispute of this kind, this should not negatively impact on the individual in need of support. In these cases, the relevant public authorities should provide the necessary care and support and then resolve amongst themselves afterwards about who should foot the bill.

The Care Act aims to try and resolve some of these issues. Under section 3 of the Care Act, local authorities are under a duty to promote the integration of support from both social care and healthcare services. This will require local authorities to take active measures to coordinate care packages and liaise with health

14. Under the Department of Health Guidance, "Ready to Go? Planning the discharge and the transfer of patients from hospital and intermediate care".

professionals where necessary.

If you are unable to resolve the matter consider making a formal complaint to both the local authority and the CCG, or if it is urgent or the complaint does not resolve things, then contact a community care solicitor to assist you. It may be important to your family member whether it is the NHS or a local authority which is legally responsible for their care, not least because local authorities can charge for most of the care they provide to disabled people whereas the NHS cannot (see above for more on this).

37. Who is responsible for leading the discharge planning and making sure everything is in place when they move out – sometimes I feel if I wasn't ringing everyday it wouldn't happen?

The discharge planning process will be led by the NHS, but it may be that the local authority needs to be involved make arrangements too (for example, to make a suitable placement available for your relative when they are discharged). Both the NHS and the local authority should be working together. If either the NHS or the local authority are causing delay, then raise your concerns with your relative's doctors or social workers first. If you are not satisfied by their response, then you can make a complaint and/or contact a specialist solicitor for advice about what steps to take next.

38. My family member is being detained in an inpatient unit and we are planning for his/her discharge. Does he/she still have a right to a needs assessment?

Yes.

The hospital should discharge your family member when it is safe to do so. This means that his/her home situation must be safe, with appropriate support in place, in order for him/her to return home. The NHS must give social services notice that your relative may need services on discharge. The local authority has a duty to conduct a needs assessment and put the care arrangements in place. Following this, the NHS must give notice to social services of the day your relative will be discharged from hospital.

If he/she is being detained under the Mental Health Act 1983, then he/she may be in need of Mental Health Act aftercare services (section 117 aftercare). This may be provided by either the local authority and/or the health authority (NHS), but importantly, this is provided without charge, whereas most local authorities will charge for other community care services they provide. This is important if your relative has any income or capital of their own.

Your family member may also be eligible on discharge to continuing healthcare ("CHC") funded by the NHS as set out above.

39. They are not involving me in all the discharge planning meetings – is there anything I can do?

Throughout the discharge planning process, your family member should be involved and their views should be taken into account by the NHS. If they have been excluded from discharge planning meetings, then raise your concerns with your relative's doctors first and make a formal complaint if you are not satisfied with their response.

If your relative lacks capacity then as stated above, under the Mental Capacity Act you should be consulted before any decisions are made in relation to discharge. You should be given the opportunity to say what arrangements you think are in your relative's best interests. If your relative lacks capacity and you have been excluded from discharge meetings, again raise your concerns with your relative's doctors first and make a formal complaint if you are not satisfied with their response.

Whether or not your relative lacks capacity, if the matter is urgent (for example, they are about to discharge your relative into a placement you think is unsuitable) then approach a specialist solicitor immediately for advice.

40. A house has been found for my family member ready for when they leave the inpatient unit, but it needs to be adapted to make sure it is safe for them. Who is responsible for getting these adaptations made and paying for them?

Ultimately whoever is responsible for funding the person's package of care (NHS or LA) has a responsibility to ensure all identified eligible needs are met.

Housing authorities and social services authorities have a duty to cooperate with one another to assess the needs of disabled adults and plan community care services. There is also a specific duty on social services authorities to facilitate adaptations that disabled people need to their homes.

If your family member's home needs to be adapted, then they or someone on their behalf e.g. you or a social worker (ultimately it is the responsibility of whoever is funding the package of care e.g. the local authority) can apply for

a disabled facilities grant under the Housing Grants, Construction and Regeneration Act 1996. These are grants that will pay towards the cost of building works necessary in order to meet the needs of disabled people. Once the local authority has carried out a needs assessment, it can make the application which is then administrated and paid by the housing authority. These grants are means tested – so the housing authority can look at your income and decide whether or not you qualify for a grant. If a grant is made but the grant is not enough to pay for the adaptations required, the local authority will have to consider how else the need is to be met – which may involve additional funding from the social care budget.

If the local authority has carried out a needs assessment, but has not applied for a disabled facilities grant, then you could write a letter to the housing authority (copying in social services) explaining what work is needed to be carried out (you shouldn't have to do this – and at this stage you could make a complaint to the LA that they haven't done it – but there is also the option of you writing to the housing authority). A professional will then be involved in the home assessment to make formal recommendations about what is required. The housing authority is responsible for all stages of the administration of the grant, and it must approve or refuse the grant application

as soon as practicable and in any event within 6 months. If you have any queries about the process or it is taking too long, then write a letter of complaint to the housing authority (copying in social services).

If the matter is very urgent, and your family member cannot wait for a full needs assessment to be carried out, then the local authority can be pressed to facilitate the adaptations. There are special provisions for urgent cases where delay will cause hardship to a disabled person. If your family member's circumstances are urgent and the situation is not moving forward and they are not responding to a letter of complaint, approach a community care solicitor for more advice.

Meeting the challenge

Ways to raise concerns and challenge decisions

Complaints processes

41. When is it appropriate to make a formal complaint and how do I do this?

A formal complaint could be about the any aspect of your family member's care and support, from abuse and neglect to delays in discharge or poor planning.

If you have not been able to resolve a dispute by talking to, or writing letters to, the public body, then you should consider making a formal complaint.

To make a formal complaint, write a letter with your name, contact details, explaining the background facts to the issue, what the current problem is, what you have done so far to try to resolve it, and what solution you are looking for.

Depending on who the complaint is against, there are various organisations that can support you to make a complaint:

- Your local PALS (Patient Advice and Liaison Service) can provide you with information, advice and support in relation to complaints about the NHS. You can find your nearest PALS online or by calling 0845 46 47 (MHS Direct).
- The Independent Health Complaints Advocacy is a free and independent advocacy service for people who wish to make a formal complaint about the NHS. It covers the South of England region only: www.seap.org.uk/services/nhs-complaints-advocacy
- NHS Complaints Advocacy Service is a free and independent service that can help you make a complaint about the NHS: <http://nhscomplaintsadvocacy.org/>
- For complaints against social services, your local authority will have a complaints procedure available on its website. This will provide you with instructions about where to send your complaint and how quickly you can expect a response.

Making a complaint will often be your first attempt to resolve the issue, before starting a claim in court. However, there are sometimes very strict time limits within which you have to start court proceedings if you are going to do so, or the matter may be too urgent to wait for a complaint.

Although it will depend upon the individual case, as a general rule, if the matter is not serious or urgent, make a complaint first. If it is serious or urgent, then you may want to approach a solicitor. The solicitor will advise you whether or not you should make a complaint.

If you are not sure what to do, contact a solicitor for advice. Most solicitors will confirm whether they can assist without charge.

Legal options

42. What is “judicial review” and when should I call a solicitor?

Judicial review is the means by which you can challenge a decision made by a public body in the court. Examples of the kinds of decisions that could be challenged by judicial review include: a cut to a disabled person’s care and support plan, removing a service provided by the local authority, or failing to provide a service when there is a legal duty to do so.

The role of the judge will be to determine whether the decision is lawful. If it is found to be unlawful, then it could be “quashed”, which means the public body will have to make a new decision. If the matter is very urgent, for example your child is about to be removed from his/her placement and you want to prevent that from happening, you may be able to get an injunction from the court. Often the threat of starting judicial review proceedings is enough to persuade the public body to behave lawfully, and most cases are settled without reaching a hearing at court.

If you think an unlawful decision has been made by a public body about your relative’s care or treatment, then call a solicitor straight away. The solicitor may tell you that it is appropriate to make a formal complaint

before taking legal action. However, there are strict deadlines for starting judicial review proceedings (this must be done within 3 months of the decision, and without delay, and the court will only extend time in limited circumstances), and so you may want to call a solicitor first to ensure you don’t miss this deadline to challenge the decision in court.

43. What is the Court of Protection and when should it become involved?

The Court of Protection is the court that deals with matters relating to people who lack mental capacity under the Mental Capacity Act 2005. A person will lack capacity to make a particular decision if he/she is unable:

- To understand the information relevant to the decision,
- To retain that information,
- To use or weigh that information as part of the process of making the decision, or
- To communicate his decision (whether by talking, using sign language or any other means).

This may be due to a learning disability, a health problem affecting cognitive abilities, or due to an acquired brain injury.

The Court of Protection deals with applications to become a financial deputy and a personal welfare deputy. For more information about when and how to become a deputy see:

www.challengingbehaviour.org.uk/learning-disability-files/18-GGetting-legal-Authority-to-make-decisions-about-money,-property-and-welfare.pdf

An application should also be made to the Court of Protection where there are particularly difficult decisions that must be made about the person’s personal welfare or where there is a disagreement (for example between a public body and family members or between family members) that cannot be resolved in any other way. Examples of the kinds of matters that should be brought before the Court of Protection include: where a local authority wants to remove the person from home and into a care home and the family disagree, the person requires serious medical treatment and it is not clear whether it is in his/her best interests, or where the person is in hospital ready for discharge and there is a dispute about where he/she should go. Applications can be time-consuming and the Court has been clear that where there is a dispute and a referral is needed, the public body should make the referral. The onus should not be on the family to do this.

The role of the judge will be to determine whether the person has capacity, and if they do not what is in the person's best interests. The Court of Protection cannot force a public body to offer a service it is not willing to provide. If families feel that their relatives should be getting more or better support than the local authority or NHS body is willing to offer, then the legal remedy is an application for judicial review.

The Court of Protection also deals with other matters, including applications to appoint a deputy, and to authorise a deprivation of liberty for situations where the Deprivation for Liberty Safeguards do not apply – e.g. in supported living. Specialist legal advice is highly recommended for any matter in the Court of Protection.

44. My family member has experienced abuse. Can I sue for the emotional trauma this has caused him/her?

Yes. The trauma may have to be evidenced by an expert report, for example from a psychologist or psychiatrist, but this is considered an injury for which you can seek compensation. You should contact a personal injury or a civil liberties solicitor to help you. The abuse may well constitute a breach of your relative's human rights. If you chose to pursue

a civil claim for compensation, your solicitor will arrange for all the necessary expert evidence to prove the abuse caused the psychological injury, and to prove what effect that injury has had on your relative.

Below is more information about how to seek compensation by making a civil claim.

45. How can I sue (make a civil claim) for compensation and is there a time limit for doing this?

If a person has suffered loss (such as a physical injury or psychological trauma) as a result of the actions of or inaction by another person or body (such as by a care agency, a hospital, or the police), that person may be able to make a civil claim for compensation.

The usual rule is that court proceedings must be started within 3 years of the event giving rise to the claim. However, sometimes court proceedings must be started much more quickly. For example, to sue a public authority for damages under the Human Rights Act 1998, court proceedings must be issued within 1 year of the event. These time limits can only be extended by the court with good reason and it should never be assumed an extension of time will be allowed

There are several different ways of funding

a civil claim. One is by legal aid (which is discussed below), another is by signing a Conditional Fee Agreement (or “no win no fee”), or you can pay privately.

If you think you may want to sue for compensation, contact a lawyer straight away. To find a solicitor, you can use the Law Society's online search engine here: www.lawsociety.org.uk/find-a-solicitor. Make sure you check the law firm's website to see whether they do similar cases to yours, and don't be afraid to shop around to find the best lawyer available.

Accessing legal support

46. What is legal aid and is my relative eligible?

If a person is eligible for legal aid, he will have his legal fees paid for by the Legal Aid Agency (LAA). This means he will not have to pay for legal advice or representation by a lawyer. Legal aid is available for all types of judicial review claim. Legal aid for other cases, for example a claim for damages resulting from abuse, may be more restricted – you will need to get advice from a legal aid lawyer to find out if the type of case you have is eligible for legal aid.

You can check whether you may be eligible for legal aid here:

www.gov.uk/legal-aid/eligibility

However, the calculation is quite complicated and so you can call a legal aid lawyer to be assessed fully. To find a legal aid lawyer, you can use the Ministry of Justice's online "Legal Aid Finder" at:

find-legal-advice.justice.gov.uk

Don't rule out the possibility that your family member or you may be able to get a lawyer. You may qualify for legal aid or there may be some other method of funding available, e.g. through a no win no fee arrangement.

Contact a legal aid lawyer or community care lawyer for advice.

For more information visit
www.mencap.org.uk/meetingthechallenge

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