Shining a light on human rights

Learning Disability and Human Rights: A practitioner's guide

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About this booklet

This booklet is about human rights in learning disability settings. It is aimed at professionals working in the community but is relevant for those working in learning disability services of all kinds. We use the term 'practitioner' throughout to include anyone working in learning disability settings (e.g. qualified and unqualified workers). Lots of information in the booklet may also be useful for learning disabled people using services, their family, carers or advocates (BIHR has also produced a range of resources aimed at people using mental health services, see www.bihr.org.uk).

This booklet was written by the British Institute of Human Rights (BIHR), in partnership with **Mersey Care Community Learning Disability Team (part of Mersey Care NHS Foundation Trust)**. The service is working with BIHR on our project called **Delivering Compassionate Care: Connecting Human Rights to the Frontline**. The project aims to place human rights at the heart of mental health and mental capacity services, helping to ensure frontline staff have the knowledge and skills to fulfil the vital role they can play in upholding the dignity and human rights of the people using their service. The project is funded by the Department of Health, therefore the information in this booklet focuses on English law and bodies.

BIHR would like to thank the practitioners from the Mersey Care Community Learning Disability Team for their help in producing this booklet, particularly the Human Rights Leads for their ideas, advice and guidance.

This booklet should be read in conjunction with our other resource **'Mental Health, Mental Capacity and Human Rights: A practitioner's guide'**. That resource contains more information about how UK law protects human rights, key rights for mental health/capacity services and where to find more information/support.

Finding your way around

Learning disability and human rights

As services committed to minimising the personal and social disadvantages experienced by learning disabled people, the aims of learning disability services align with human rights values. This includes supporting people to:

- exercise freedom and autonomy with minimal unwanted interference from others
- overcome the obstacles to accessing the places, people and services that are available to everybody
- minimise the use of restrictions imposed by others to deal with the day to day challenges associated with learning disability

Independence, autonomy and equality are all key human rights values, protected by rights in the Human Rights Act 1998. This booklet aims to give practitioners the knowledge and confidence to use human rights in practice to design and deliver rights-respecting learning disability services. It focuses around three key issues for learning disability services, identified by our partner. Other key issues relevant to learning disability services are covered in another booklet in this series, **'Social Care Intervention and Human Rights: A practitioner's guide'**.

one	Responding to behaviours of concern	Page 3
	Decision-making flowchart	Page 6
two	Responding to breakdown in care arrangements	Page 10
three	Working with learning disabled people in relationships where risk is a factor	Page 13

 $\begin{pmatrix} 1 \end{pmatrix}$ This booklet is for information purposes only. It is not intended, and should not be used, as legal advice or guidance.

one

Responding to behaviours of concern

Responding to behaviours of concern in a learning disability setting may raise human rights issues. Use of techniques such as supervision and restraint might involve interference with human rights. Sometimes those restrictions may be necessary to protect people from harm. However this needs to be carefully balanced against people's right to liberty and to autonomy (protected by the right to respect for private life). A human rights approach to this issue would include assuming from the outset that the behaviour is a meaningful and autonomous act on the part of the person and that practitioners might need to take positive steps to understand its meaning when working out how best to respond.

Potential human rights issues for practice

- applying blanket policies or standardised ways of responding to all incidents of behaviours of concern, for example routinely using 'time out' interventions regardless of the impact on the person
- using restrictive interventions in response to behaviours of concern, for example increased supervision over a long period of time without having made any serious attempt to understand the meaning of the behaviour
- people not being supported to exercise their autonomy by communicating a personal view or preference in a way that others will understand
- people experiencing preventable suffering as a result of unmet physical or mental health needs that go undetected or misdiagnosed due to a failure to understand the meaning of behaviours of concern

A human rights approach to responding to behaviours of concern

This could include:

~	taking positive steps to involve people in decisions about their care – this could include providing relevant information accessible to the person and ensuring they have access to someone who can be an effective advocate by promoting their wishes and their best interests if necessary
~	taking the behaviour seriously as a communicative act to express a thought, feeling, wish or preference, in the context of what is known about the person's current circumstances and views
•	 paying close attention to what the behaviour could mean for the person when working out the best way to respond to it, including whether: any restrictive measures will interfere with their human rights and whether there are other, more rights-respecting options planned interventions are targeting the right problem and are therefore likely to achieve their aim any steps taken to resolve the issue are proportionate to the nature and seriousness of the risk
~	ensuring that one of the aims of intervention is to support the person to exercise their autonomy through self management

Key rights for responding to behaviours of concern

Right to respect for private life

(protected by Article 8 in the Human Rights Act)

This right protects people's **autonomy** including:

- people having control over their own life, care and treatment - the starting point should be that the person has capacity to do so
- respecting the ability of people with capacity to take risks and make their own decisions
- where a person is assessed as not having capacity to make a decision, supporting them to have as much control over their own live, care and treatment as possible

This right also protects people's **well-being**, including:

- people being free from abuse or neglect (including from other individuals or staff members)
- a person exhibiting behaviours of concern because they are suffering mental or physical pain

This right also protects people's right to participate in the life of their community, including if they are unable to do so as a result of their behaviour, or may need support to do so.

Relevant practitioners' duties:

to respect this right: not interfering where possible unless it is lawful, for a legitimate reason and proportionate

to protect this right: taking action to protect where necessary

See our other booklet 'Mental Health, Mental Capacity and Human Rights: A practitioner's guide' page 17 for more information, including your other duties.

Right to liberty (protected by Article 5 in the Human Rights Act)

This right prevents extreme restrictions being placed on people's movement, except in specific circumstances (such as a Deprivation of Liberty (DoL) authorisation or detention under the Mental Health Act 1983). Even if a restriction on liberty is for a lawful reason, there are still human rights safeguards which must be in place. In learning disability settings, this could cover:

- restrictive interventions that involve removing a person to a room for 'time-out'
- a person being under constant supervision or control of staff and not free to come and go from a place – this will amount to a deprivation of liberty requiring a DoL authorisation ('Cheshire West' case, 2014)
- use of tranquilising psychiatric medication to address behaviours of concern

Relevant practitioners' duties:

- O to respect this right: not interfering where possible
- to protect this right: applying the procedural safeguards written into the right

- 1 See our other booklet 'Mental Health, Mental Capacity and Human Rights: A practitioner's guide' page 15 for more information, including your other duties.

Right to be free from inhuman or degrading treatment

(protected by Article 3 in the Human Rights Act)

This right could be relevant where a person is at risk of serious harm, including:

- a person in your care being at risk of self-harm or harming others
- a person exhibiting behaviours of concern because they are suffering severe mental or physical pain



Right to non-discrimination (protected by Article 14 in the Human Rights Act)

This right not to be discriminated against in relation to any of the rights in the Human Rights Act could cover:

- a person being denied access to services or treatment because they are learning disabled, or because they exhibit behaviours of concern
- learning disabled people being more likely to face more severe restrictions, for longer than others under comparable circumstances

See our other booklet 'Mental Health, Mental Capacity and Human Rights: A practitioner's guide' page 20 for more information.

Worked example

to change the walking route. She considers Erik, a 26 year old learning disabled man, lives his behaviour to be a reasonable attempt to in 24 hour supported housing. He goes for communicate his feelings on the issue. Parveen a walk to town each morning with a support proposes a solution to balance the need to worker to get a drink from a particular cafe. protect Erik and others from harm, whilst Recently staff decided, without consulting respecting his right to private life. The new Erik, to change the route and avoid the town plan lifts the restriction on going to town but centre. This is after Erik ran away from his changes the walk to a guieter time when there support worker in town three times. Erik is are fewer people and less traffic, reducing the not happy about the decision and there have risk of harm should Erik run away. been escalating incidents every day ever since. Parveen, a learning disability practitioner, speaks to Erik and the staff team and discovers that Erik's behaviour became more concerning at the time of the decision



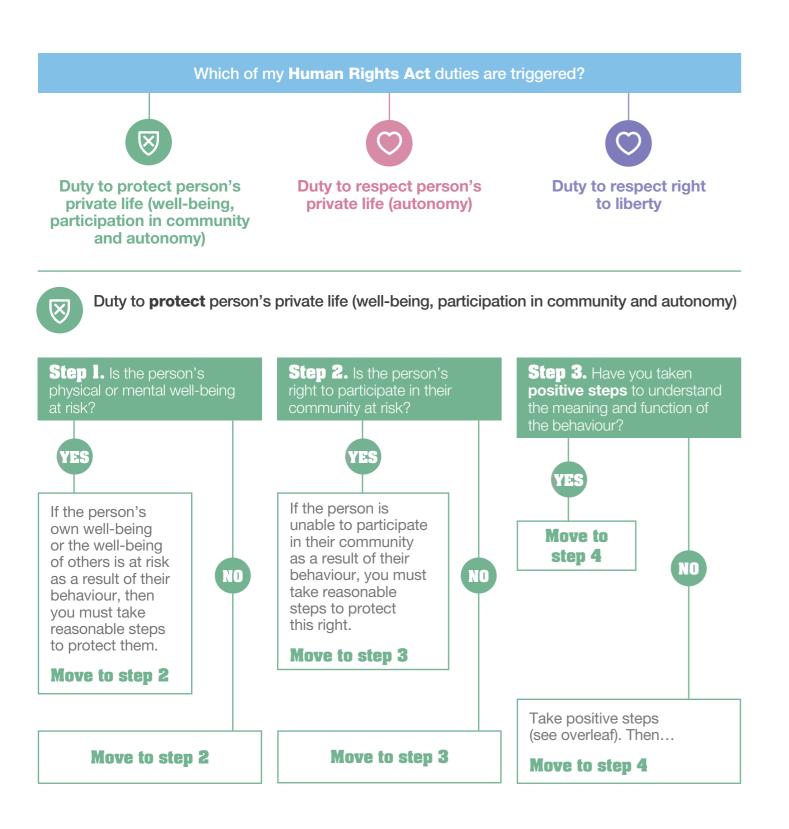




🔘 to respect this right: not breaching where possible

to protect this right: taking into account that sometimes people need to be treated differently, because their situation is different

ONE: Decision-making flowchart



Responding to behaviours of concern in a learning disability setting

This flowchart is for practitioners working in learning disability settings, to help you use a human rights approach to responding to behaviours of concern



The person's right to respect for private life is not an absolute right; you must follow the three stage to see if your interference would be permissible:

- 1. Lawful: the Mental Capacity Act will only permit you to interfere with the person's autonomy if they lack capacity to make that decision. If not already done so, arrange a mental capacity assessment. If assessed as not having capacity, make a best interests decision that aims to protect the person's right to autonomy as much as possible.
- Legitimate aim: is your planned intervention likely to protect the person/ others' well-being?
- 3. Proportionate: will the interference be proportionate to the seriousness of the harm it is aiming to prevent?

Move to step 5







755

Duty to **respect** person's right to liberty

Step 5. In taking steps to prevent risk to the person's well-being, are you at risk of depriving them of their liberty?

If your restriction of the person's liberty doesn't amount to a 'deprivation of liberty', you will need to refer to your internal policies on seclusion, restraint etc. to apply the correct procedural safeguards ensuring any restrictions on the person's liberty are lawful.

Yes: the right to liberty can be limited. But first, you should take all practicable steps to avoid this and only deprive someone of their liberty if:

- the person is assessed as lacking capacity to make the decision
- the person needs care or treatment to protect them from harm or abuse and there is no other way to provide it
- a best interests decision has been made to deprive them of their liberty

Obtain deprivation of liberty authorisation

Explaining the steps in the flowchart



Step I. Is the person's physical or mental well-being at risk?

The duty to protect a person's right to private life includes protecting their well-being. This could mean protecting somebody from risk of assault, intimidation or fear as these are all likely to have an adverse effect on a person's ability to function independently. If the risk is very severe leading to serious injury or suffering, then the duty to protect a

person from inhuman and degrading treatment may be more relevant.

The 'reasonable steps' taken to prevent a risk to well-being must be necessary and proportionate to the risk and must not cause the person more harm than they aim to prevent.



Step 2. Is the person's right to participate in their community at risk?

If a person's behaviour has led to a community-based activity being stopped or if it has necessitated a move away from as finding an alternative, overcoming their community, their right to participate in the life of their community (part of the right to private life) may be at risk. Reasonable steps to address this could

include taking additional measures to support community participation such obstacles to continue participation or in the event of a move, identifying placements in communities that people can realistically access and be a part of.



Step 3. Have you taken positive steps to understand the meaning and function of the behaviour?

The right to respect for private life protects As well as being more respectful of a people's autonomy. It places a positive obligation on practitioners to take steps in situations where this right is at risk. In a learning disability setting, it is likely that there will be obstacles to communication and it would be unreasonable not to take this into account when working out how to respond to behaviours of concern. The positive steps it would be reasonable to take in this situation could involve attempting to understand the meaning and function of the behaviour.

person's autonomy, this approach is also likely to lead to greater insight. It should also lead to a wider range of less restrictive options for intervention, for example, changing something about the environment, the care arrangement or the way that the person adapts their response to a particular trigger.

ONE

a behaviour-related issue?

Autonomy (part of the right to private life) means the person should be free to make their own choices and decisions. free from outside interference. A human rights approach to assessing capacity would recognise the importance of effectively applying the safeguards in the Mental Capacity Act 2005 (MCA) to respect the person's autonomy. This could include taking all practicable steps to support the person to make a decision. seeking to involve advocates in capacity assessments and best interests, and applying the principle of least restriction when considering any interventions in the person's life.

If a person is assessed as having capacity to make the decision to behave in a certain way, practitioners would need to respect the decision and find alternative ways to address any risks associated with the behaviour. For example by providing advice and support or making changes with the person's consent.

of depriving them of their liberty?

A person is deprived of their liberty

- a person is under constant super or control: and
- not free to leave a place (with the being not on whether a person ap to want to leave, but on how the around them would react if they d attempt to leave); and
- public officials are involved in the funding, arrangement, planning a delivery of the person's care

(Cheshire West and Chester Council v P, 2014)



Step 4. Are you considering intervening in the person's private life to resolve

If a person is assessed as not having capacity, a best interests assessment is needed to determine a course of action that should respect the person's wishes and autonomy whilst also addressing any concerns about the possible consequences of their behaviour. The MCA sets out how to make a best interests decision in a way that respects the person's right to private life. Three important points to remember when doing this:

- 1. The MCA prohibits professionals from make a best interests decision with the primary aim of protecting others from harm as action taken on these grounds cannot really be said to be in the person's best interests.
- 2. Working out the least restrictive approach to achieve the aim of the intervention will help to ensure that any interference is proportionate to the seriousness of the risks involved.
- 3. The effort expended in working out a person's best interests should be proportionate to the seriousness of the decision(s) being made.

Step 5. In taking steps to prevent risk to the person's well-being, are you at risk

where:	Where a person is being deprived of their
rvision	liberty, practitioners need to follow the legal safeguards in the MCA and apply
	for a Deprivation of Liberty authorisation.
e focus	Internal policies should set out the steps
ippears	taken by staff to protect the person's right
people	to liberty when other types of restraint
did	and restriction are used in response to
	behaviours of concern. However, these
1	internal procedures still need to comply
, and/or	with the safeguards in the right to liberty.

Responding to breakdown in care arrangements

Responding to a breakdown of care in a learning disability setting might raise human rights issues. Practitioners' involvement may come at a time of crisis for the person and for those around them. The tendency could be for interventions to become more restrictive in the attempt to manage increased risks. For some practitioners delivering these interventions, they may not feel equipped to provide the specialist support needed. There is likely to be uncertainty about what happens next and with all these factors combined, the resulting sense of urgency can work against rights-respecting decisions that seek to carefully balance concerns about risk with the person's rights. A human rights approach to this issue would recognise the urgency of the need to act to protect people from harm, whilst having regard to the impact on the person of any life changing decisions in response to a breakdown of care.

Potential human rights issues for practice

- people being moved to unsuitable living placements where a further breakdown of care arrangement is likely
- people being moved away from their homes and/or their communities to receive specialist support
- failing to take reasonable steps to prevent a breakdown of care
- people living in excessively restrictive environments for long periods of time in response to care arrangements breaking down

A human rights approach to responding to breakdown in care arrangements

This could include:

- ✓ taking early positive steps to avert a predictable breakdown of care arrangement
- \checkmark personalising care to the person, especially any potential restrictive interventions that feature as part of the care plan
- understanding how different care arrangements are likely to impact on the rights of the person and advocating for the most rights-respecting option
- delivering any interventions in the least restrictive setting such as in the person's home, a place known to them or somewhere in their community
- bringing in specialist support, care or treatment to the person's home environment rather than requiring them to move to another care setting to access it
- where a change of living arrangement is necessary, taking all steps to find a suitable placement within the person's community, close to their family

two

Key rights for responding to breakdown in care arrangements

Right to respect for private and family life and for home

(protected by Article 8 in the Human Rights Act)

This includes:

- private life protects people's autonomy, including having control over their own life, care and treatment and practitioners taking positive steps to identify risks and prevent the need for more serious interference in future
- **family life** includes taking steps to keep people close to their family following a breakdown of care arrangement and family members being consulted on important decisions that will affect their right to family life
- **home** includes respecting a place that the person considers their home, (which could include a residential home or other care setting) and carefully considering all other options before removing a person from that place

Right to liberty (protected by Article 5 in the Human Rights Act)

This right prevents extreme restrictions being placed on people's movement, except in specific circumstances (such as a Deprivation of Liberty (DoL) authorisation or detention under the Mental Health Act). Even if a restriction on liberty is for a lawful reason, there are still human rights safeguards which must be in place. In learning disability settings, this right could include:

- ensuring that people are living in the least restrictive environment to meet their needs at any given time
- taking steps to make sure that a person is not deprived of their liberty without the proper legal safeguards to authorise this



Relevant practitioners' duties:

- to respect this right: not interfering where possible unless it is lawful, for a legitimate reason and proportionate
- 🗵 to protect this right: taking action to protect where necessarv

See our other booklet 'Mental Health. Mental Capacity and Human Rights: A practitioner's guide' page 17 for more information, including your other duties.



- (O) to respect this right: not interfering where possible
- 🗵 to protect this right: applying the procedural safeguards written into the right

See our other booklet 'Mental Health, Mental Capacity and Human Rights: A practitioner's guide' page 15 for more information, including your other duties.







two

three



Right to be free from inhuman or degrading treatment

(protected by Article 3 in the Human Rights Act)

This right could be relevant where a person is at risk of serious harm, including:

- an environment has put people at risk of serious harm as a result of risks associated with an inappropriate care arrangement
- serious mental or physical suffering as a result of a breakdown in care arrangements

Relevant practitioners' duties:

- to respect this right: not breaching in any circumstances
- to protect this right: taking action to protect someone from a known and immediate risk of serious harm, often called **safeguarding**

See our other booklet **'Mental Health, Mental Capacity and Human Rights: A practitioner's guide' page 12** for more information, including your other duties.

Worked example: breakdown in care arrangements

Reza, a 31 year old learning disabled man with autism, lives in a 24 hour supported house. Sue, a learning disability practitioner, responds to reports from the service provider that Reza's care arrangement has broken down. When Sue visits, Reza has destroyed most of his belongings and is refusing all contact after losing control and hitting a support worker. The service provider and Reza's family are strongly recommending that he is moved to a new, more secure placement. Reza is assessed as not having capacity to decide whether he should move.

Sue speaks to Reza, his family and support workers to gain a better understanding of the significance of the behaviour. Sue learns he has experienced several changes of living placement following similar crises in the past. She also observes a pattern in events preceding the crisis with similar concerns being raised, but not addressed at an early stage. After speaking to Reza again, Sue puts in place a positive behavioural support plan. It recommends small adaptions to Reza's environment and care arrangement with minimal interference to his autonomy and private life. Sue invites a local specialist practitioner to work with the service provider to deliver specialist support for Reza.

In response to the risk to others, Sue looks closely at the incident of assault and the possible factors. Sue ensures the behavioural support includes preventative and responsive actions that staff can take in future. This includes training for the support team in the safe use of restraint and ensuring they are aware of internal policies for responding to physical aggression in a rights-respecting way. Sue also takes positive steps to reduce the risk of similar situations arising in future by meeting the local authority and advocating for the most rightsrespecting care arrangement should the current plan not be effective.

"I was able to use human rights arguments to get appropriate care for a patient who was relapsing in our service. There was a delay in getting him transferred to an appropriate setting due to a disagreement between two Trusts about funding. I was able to point out the delay meant that he was being left in circumstances that were degrading. We used the right to be free from degrading treatment and right to respect for private life to get the matter resolved urgently."

Practitioner on BIHR's Delivering Compassionate Care project

Learning disabled people and 'unwise decisions' about relationships

Learning disabled people enjoy the same human rights as everybody else. This includes the right to form relationships and the right to make their own decisions, even where others might think these 'unwise'. When an 'unwise decision' refers to a relationship, for example with a potentially abusive partner, this will require a careful balancing of rights. On the one hand this issue might require practitioners to take reasonable steps when they know someone in their care is at risk of serious abuse. But this will need to be carefully balanced against the person's right to autonomy, including the right of a person who is deemed to have capacity to take risks.

"We used the right to respect for private life and family life to challenge Commissioners who had issued a blanket policy stating 'no residents are allowed to have overnight visitors' in relation to a supported living scheme. The residents have their own tenancy within the supporting living scheme and it was their home."

Practitioner on BIHR's Delivering Compassionate Care project

Potential human rights issues for practice

- a person's living and/or support arrangements having the unintended effect of restricting their freedom to form and maintain personal relationships, for example if support staff prohibit a partner suspected of abuse from entering the building, inadvertently resulting in restricted contact
- an assessment of capacity to make a decision on contact or sexual relations with a particular person focusing on the assessor's concerns about the choice of partner, rather than on the person's capacity to make the decision
- blanket approaches where practitioners see it as their duty to intervene and prevent people from having relationships which they consider to be unwise, without assessing the risk of harm and taking into account that people with capacity have a right to make unwise decisions
- standardised responses to relationships in a learning disability setting, characterised either by disproportionate interference where people are assessed as lacking capacity on this decision, or failing to act to try and prevent serious risk where a person has capacity

Key rights for learning disable people and 'unwise decisions' about relationships

Right to respect for private and family life

(protected by Article 8 in the Human Rights Act)

This includes:

- private life protects people's autonomy, including people having control over their own life and decisions and people with capacity being free to take risks in relationships
- **family life** includes forming and maintaining relationships and people being able to enjoy their family life/relationships, free from outside interference

Relevant practitioners' duties:

- to respect this right: not interfering where possible unless it is lawful, for a legitimate reason and proportionate
- to protect this right: taking action to protect where necessary

See our other booklet 'Mental Health. Mental Capacity and Human Rights: A practitioner's guide' page 17 for more information, including your other duties.

A human rights approach to working with learning disabled people in relationships where risk is a factor

This could include:

- ✓ starting from the assumption that until proven otherwise, both people in the relationship are able to make their own decisions, including those about relationships and decisions considered unwise by others – where you have genuine concerns there should be a capacity assessment under the Mental Capacity Act
- respecting the decision of a person deemed to have capacity to continue having contact with a partner, even if this is considered unwise under the circumstances
- understanding the difference between support, persuasion and coercion when assisting a person to make a decision about whether or not to continue with a relationship considered unwise

- ✓ being mindful of rights-respecting practice when assessing capacity to consent to sexual relationships with a particular person, keeping in mind that "capacity to consent to sexual relations is issue specific; it is not person (partner) specific" (Local Authority X v MM & KM, 2007)
- taking reasonable steps to respect the wishes of a person assessed as lacking the capacity to decide on contact with a partner, even if they are considered unwise under the circumstances
- ✓ making it easy for people to access independent advocacy in situations where their decision to continue a relationship is contested on grounds of capacity
- ✓ supporting people to exercise their freedom to make informed decisions about relationships throughout their lives, for example by providing accessible information and peer support on relationship issues

three

Right to be free from inhuman or degrading treatment

(protected by Article 3 in the Human Rights Act)

This right could be relevant where a person is at risk of serious harm. It includes a positive obligation to take reasonable steps to protect a person in your care from immediate risk of serious abuse, including:

- serious harm from abuse or exploitation in a relationship
- continuing to monitor any risk of abuse after a person has been assessed as having capacity to decide on relationships

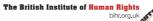
Where a person is at risk of less serious abuse, this could engage your duty to protect their well-being under the right to respect for private life.



In real life: learning disabled people and 'unwise decisions' about relationships

Melissa is a 45 year learning disabled woman with a diagnosis of schizophrenia. She has recently moved from her own flat to supported accommodation after many years of living independently with an abusive partner, Keith. In the past Keith has encouraged Melissa to disengage from psychiatric services which resulted in a deterioration of her mental health. He has been diagnosed with a psychopathic personality disorder and alcohol misuse.

The local authority applied to the court, seeking an order that Melissa doesn't have capacity to make decisions about contact. residence, marriage and sexual relations or to conduct litigation.





Relevant practitioners' duties:

to respect this right: not breaching in any circumstances

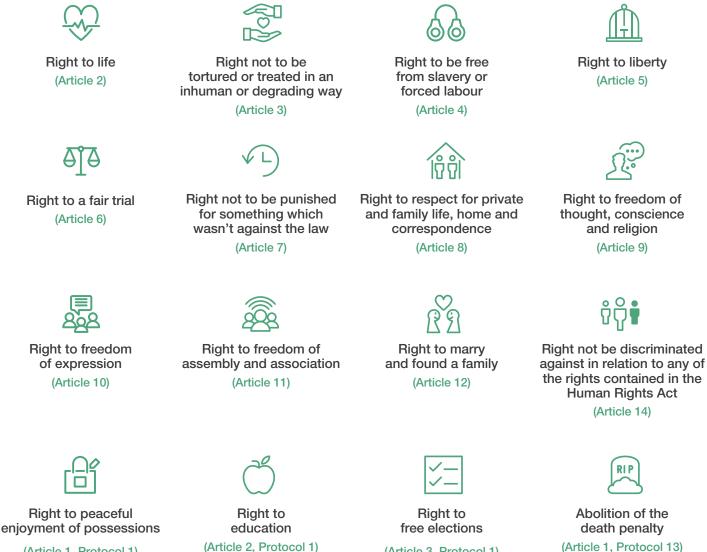
() to protect this right: taking reasonable steps to protect someone from a known and immediate risk of serious harm, often called safeguarding (reasonable steps could include using safeguarding protocols)

See our other booklet 'Mental Health, Mental Capacity and Human Rights: A practitioner's guide' page 12 for more information, including your other duties.

- The court decided that Melissa lacked capacity concerning litigation, residence and contact but not about sexual relations. The court decided that it was in Melissa's best interests to remain in supported accommodation but only if she had access to sufficient contact, and the ability to have a sexual relationship, with Keith.
- The judge ruled "we need to be careful not to embark upon social engineering. And we should not lightly interfere with family life...the court must be careful to ensure that...it does not expose [someone] to the risk of treatment at the hands of the state which, however wellintentioned, can itself end up being abusive of her dignity, her happiness and indeed her human rights. What good is it making someone safer, if it merely makes them miserable?"
- (Local Authority X v MM, KM, 2007)

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The rights protected by our Human Rights Act:



(Article 1, Protocol 1)

(Article 2, Protocol 1)

(Article 3, Protocol 1)

This booklet has been produced for staff delivering health and care services. If it has helped you to deliver rights-respecting care BIHR would love to hear your examples. You can email your real life examples of positive changes to your practice on info@bihr.org.uk.

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