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Our Charter of Ambition and Rights for Personalisation Legal Guidance Toolkit Published November 2018

Personalisation is about achieving choice and control in many ways and in different settings to empower and enable an individual. Personalisation should attempt to remove barriers so an individual can access their community, feel included and do the ordinary or extraordinary activities they choose to do.

Social care and legislation are moving towards this model of care. However one has to be mindful that there can sometimes be a gap between the reality and legislation, policy and best practice. This document provides further legislative information and policy to support the ambitions shared in the Peer Support Network **Charter of Ambition and Rights for Personalisation**. Legal guidance notes in this toolkit have been compiled by community care lawyer, Carolyn Hunnisett.

Key legislation that should assist or protect individuals are:

- **The Equality Act 2010** – Disability discrimination is when you are treated less well or put at a disadvantage for a reason that relates to your disability. Disability one of the protected characteristics covered by the Equality Act. The treatment could be a one-off action, the application of a rule or policy or the existence of physical or communication barriers which make accessing something difficult or impossible.
- **The Children and Families Act 2014** - creates a new 'birth-to-25 years' Education, Health and Care Plan (EHCP) for children and young people with special educational needs and offers families personal budgets so that they have more control over the type of support they get.
- **The Care Act 2014** - The Care Act has introduced new eligibility criteria to assist Local Authorities in deciding who is eligible for care and support. Adults with a physical or learning disability or illness who are unable to complete specific tasks or activities are likely to meet the criteria where they have care and support needs.

- **The Health & Social Care Act 2012** – A piece of legislation restructuring the NHS and in theory putting the commissioning power into the control of local NHS Clinical Commissioning Groups therefore leading to a “more personalised” approach.

Support

Ambition

I want to understand how I can use a Personal Health Budget (PHB) and I want it to be structured in a way so that it does not limit my life choices and quality of support.

Legal Guidance

The Care Act 2014, which came into force in April 2015, represents the biggest reform of care and support since 1948, reshaping the system around prevention and promoting individual wellbeing. Personalisation is at the heart of the Act, which:

- Enshrines in law the duty to prevent, reduce and delay people’s need for formal services, including considering the role of communities and local networks and resources in helping people stay independent for longer.
- Requires there to be universal information and advice available locally to help people understand how to access care.
- Describes how local authorities should work with providers of care and support to develop services to meet people’s needs and preferences.
- Modernises the right to assessments, ensuring a focus on the person’s needs and outcomes and their involvement in the process, whilst providing flexibility to align and integrate assessments to fit around the person.
- Provides new entitlements to personalised care and support plans, which can be integrated with other plans, setting out how needs will be met.
- Enables people and carers to expect similar levels of care and support when moving areas.
- Confirms personal budgets in law for people with eligible assessed needs and carers, including the right to direct payment.

<https://www.england.nhs.uk/wp-content/uploads/2014/09/tlap-getting-serious.pdf>

The Health and Social Care Act 2012 gave commissioners a duty to promote the involvement of individual patients in decisions relating to their care and the NHS Mandate includes an objective to radically increase people's control of their care and to extend the use of personal budgets.

The Children and Families Act creates a new 'birth-to-25 years' **Education, Health and Care Plan (EHCP)** for children and young people with special educational needs, and offers families personal budgets so that they have more control over the type of support they get. In some cases, where a person is over 18, the 'Care' part of the **EHC plan** will be provided for by adult care and support, under the Care Act.

The Children and Families Act also improves cooperation between all the services that support children with special educational needs and their families. This requires local authorities to involve children, young people and parents in reviewing and developing care for those with special educational needs. Local authorities will also need to publish information about what relevant support can be offered locally.

Practical support

What is a personal health budget? (NHS guidance)

<https://www.nhs.uk/using-the-nhs/help-with-health-costs/what-is-a-personal-health-budget/>

What is Self-Directed Support? (In Control easy read booklet)

<http://www.in-control.org.uk/media/20103/7%20steps%20easy%20read%20booklet%20.pdf>

The young person's guide to the Children and Families Act 2014

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/359681/Young_Person_s_Guide_to_the_Children_and_Families_Act.pdf

Ambition

I want support during the transition from school to adult life including access to information on the full scope of what is available to me.

Legal Guidance

Transition into adult social care:

The Care Act 2014 places a duty on local authorities to conduct transition assessments for children, children's carers and young carers where there is a likely need for care and support after the child in question turns 18 and a transition assessment would be of 'significant benefit'. Early transition planning is important in helping prevent a gap in service. It considers the young person's well-being and what care and future support they will need. Under the Care Act, Local authorities must: 'establish and maintain a service for providing people in its area with information and advice relating to care and support for adults and support for carers'.

A young person or their carer can make a referral to Adult Social Care and request a transition assessment. The young person and carer must be in agreement and give consent for the referral where they are able to do so. The assessment usually involves the young person, their parents, carer and anyone else the person, parents or carer asks to be involved. For young people with Special Educational Needs and who likely to have Care and Support Needs at 18, a joint assessment and transition planning may be appropriate. If an assessment is not needed then the reasons for this will be given along with advice and more information.

If an Educational, Health and Support Plan is in place, this is a legal document which should look holistically at the needs of a young person going forward. If an assessment has not been conducted you have a legal right to appeal.

Practical support

Pre School transitions

https://www.csu.edu.au/_data/assets/pdf_file/0004/517036/Facilitating-Childrens-Trans-School.pdf

For a guide to transition from childhood to adulthood:
<https://councilfordisabledchildren.org.uk/transition-information-network/information-and-support/transition-guides>

To access Independent support for EHC plan see:
<https://councilfordisabledchildren.org.uk/independent-support>

Ambition

I want people involved in decisions about my care to be better informed about complex needs and disability rights to ensure that I am not discriminated against

Legal Guidance

Health & social care professionals need to ensure that they are working within their professional codes of conduct and meeting their competencies. Professionals are required to keep up with Continuing Professional Development (CPD), continuing professional development. They should not work in an area that means they are acting beyond their scope and practice. **The Equality Act 2010** should offer protection for people with disabilities and their carers, to ensure they are not discriminated against.

Ambition

I want a personalised support plan that fully takes into consideration my needs and ambitions for my life

Legal Guidance

A personalised support plan is an holistic approach that should take account of a person's needs and wants in the context of their life, environment and social setting.

A coalition of health and social professionals and charities developed a toolkit to support the move towards person-centered care and support planning.

For an Adult the Care Act aims to follow a person-centered care planning approach.

For children with Special Educational Needs (SEN) their Education,

Health and Care plan developed from the Children and Families Act aims to:

- “get education, health care and social care services working together
- tell children, young people and their parents what they need to know about their disability or special educational needs
- make sure children, young people and families know what help they can get when a child or young person has special educational needs or a disability make sure that different organisations work together to help children and young people with special educational needs
- give children and young people and their parents more say about the help they get
- set up one overall assessment to look at what special help a child or young person needs with their education, and their health and social care needs, all at the same time
- give a child or young person just one plan for meeting their education, health and social care needs, which can run from birth to age 25 if councils agree that a young person needs more time to get ready for adulthood
- make sure children, young people and their parents can choose some of the help they need
- provide ways to help sort things out if a child or young person or their parent needs to appeal about the help they get”.

Practical support

Personalised care and support planning handbook (NHS England)
<https://www.england.nhs.uk/ourwork/patient-participation/patient-centred/planning/>

Local East Sussex guide to the application process for an EHCP:
https://www.eastsussex.gov.uk/media/12021/guide-to-ehc-assessment-process_0001.pdf

Ambition

I want continuity of record keeping which is easy to access so people know my situation

Legal Guidance

There is currently a massive culture shift to realising that health and social care information/assessment should be joined up and non repetitive. There are several task forces at the moment, trying to implement this including the Professional Records Standards Body. More recent legislation such as the Children's and Families Act have created documents such as the EHCPs to ensure records follow individuals through education.

Practical support

Professional Record and Standards Body
<https://theprsb.org/usingstandards/>

Community

Ambition

I want my son to be involved in community events

Legal Guidance

If participation in community events is identified as a need under the principle of the **Care Act 2014**, as an adult this should be facilitated to promote social inclusion. Under the Children and Family Act 2014 this should be facilitated as part of a child or young person's EHC plan.

A community event/group and or organisation cannot discriminate against a person due to their disability (**Equality Act 2010**).

Practical Support

Document for practitioners about how to promote community inclusion
<https://www.scie.org.uk/publications/guides/guide16/tasks/inclusion.asp>

Ambition

I want higher visibility and integration of people with learning disabilities in the community life

Legal Guidance

Personalisation is the central principle of the **Care Act 2014**, which enshrines in law the duty to prevent, reduce and delay people's need for formal services, including considering the role of communities and local networks and resources in helping people stay independent for longer.

Ambition

I want community services including the police force to be personalised so we know the people and not the organisation

Legal Guidance

Police need to follow the principles of legislation and follow the person centred approaches extolled in recent Acts of parliament such as the Care Act 2014 etc. Police officers need to follow safeguarding processes and procedures.

Disability Engagement Officers are in place within the Police force to raise their knowledge and understanding, and create awareness in physical and learning disabilities. DEOs act as a point of contact for disabled communities and individuals, building relations to increase trust, confidence and encourage reporting of crime.

Practical Support

Making Safeguarding Personal: what might 'good' look like for health and social care commissioners and providers?

<https://www.local.gov.uk/making-safeguarding-personal-what-might-good-look-health-and-social-care-commissioners-and>

Equality and Diversity - disability and mental health (Sussex Police)

<https://sussex.police.uk/about-us/governance-and-processes/equality-and-diversity/equality-and-diversity-disability-and-mental-health/>

Ambition

I want to ensure people are valued as part of their community and that people overcome their fear of difference

Legal Guidance

The **Equality Act 2010** promotes inclusion with people with disabilities. For instance by ensuring employers offer reasonable adjustments so disabled people can become part of the workforce. That housing and access to public buildings consider the needs of disabled people. That clubs do not exclude certain protected characteristics.

Practical Support

Achieving inclusion in community life (Social Care Institute for Excellence)

<https://www.scie.org.uk/publications/guides/guide16/tasks/inclusion.asp>

Ambition

I want more exposure for people from a young age to people with learning disabilities to change the idea of 'normal'

Legal Guidance

The **Equality Act 2010** promotes inclusion with people with disabilities. With access requirements to public buildings and facilities, traditional barriers are being removed. However, it is a societal shift that still needs work and advocacy to change attitudes. The Act says schools mustn't discriminate against a pupil because of their disability. This is unlawful under the Act. In some situations, schools must also take positive steps so that disabled pupils can access and participate in the education and other activities they provide.

Practical Support

Resource with pack to help teach children about this matter:

<http://disabilityactionalliance.org.uk/resources/disability-awareness-for-children/>

Disability discrimination in schools (Citizens Advice)

<https://www.citizensadvice.org.uk/family/education/discrimination-in-education/disability-discrimination-in-schools/>

Housing

Ambition

I want to live independently at home with skilled support as and when I need it

Legal Guidance

Minor or major adaptation's can help you live in your home. If you meet the criteria of the Care Act and your financial needs are assessed you can, as an adult, be supported with your identified needs. If you have met the criteria for NHS CHC funding you could be provided with healthcare support.

Local authorities are under a duty to assess your social and health care needs in line with the person centred approaches in the **Care Act 2014**. Daily equipment and adaptations need to be provided if they meet your needs. You are not required to cover the cost of if the minor adaptations is less than £1000.00. If the adaptations cost more than a £1000.00 you can apply for a Disabled Facilities Grant.

Practical Support

Personal Budgets helpline (Disability Rights UK)
<https://www.disabilityrightsuk.org/how-we-can-help/helplines/independent-living-advice-line>

Disabled Facilities Grant
<https://www.gov.uk/disabled-facilities-grants>

For a child:
<https://www.gov.uk/help-for-disabled-child/home-adaptations>
<https://www.scope.org.uk/support/disabled-people/independent-living-guide>

Independent Living (SCOPE)
<https://www.scope.org.uk/support/disabled-people/independent-living/housing>

Ambition

I want a choice of housing options within my community for my sister so she can live near her family

Legal Guidance

Under the **Care Act 2014**, if an assessment identifies this is a need for a person this should be facilitated as much as possible.

Practical Support

Independent Living (SCOPE)

<https://www.scope.org.uk/support/disabled-people/independent-living/housing>

Housing for people with a learning disability (MENCAP)

https://www.mencap.org.uk/sites/default/files/2016-08/2012.108-Housing-report_V7.pdf

Ambition

My daughter would crumble if she moved from home, she needs someone to help her understand different options for the future

Legal Guidance

The Local Authority must provide free information and advice about options available to people in the community such as housing and provision of care. An occupational therapist can see if there are aids or adaptations to the home to prevent unnecessary moves.

The Local Authority can assess the needs of any carers (**Care Act 2014**) if that would help facilitate loved-ones staying at home.

Practical Support

Independent Living (SCOPE)

<https://www.scope.org.uk/support/disabled-people/independent-living/housing>

Housing options for people with a learning disability

<https://www.scope.org.uk/support/disabled-people/becoming->

Ambition

We want people to have their skills assessed periodically and be given the opportunity to move onto new housing opportunities and to develop new skills

Legal Guidance

Care plans and assessments should be regularly reviewed and updated to see what's working and not working, and if it's still the best support for the individual. This usually happens within the first few months of support starting and then once every year.

Under the **Care Act 2014**, the Local Authority has a legal responsibility to review care plans to make sure needs and outcomes continue to be met over time. If anything has changed, the authority must carry out a new assessment. You have the right to request a review of your care and support plan.

Practical Support

Independent Living (SCOPE)

<https://www.scope.org.uk/support/disabled-people/independent-living/housing>

Housing for people with a learning disability (MENCAP)

https://www.mencap.org.uk/sites/default/files/2016-08/2012.108-Housing-report_V7.pdf

Care Act factsheets (Updated 19 April 2016)

<https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets/care-act-factsheets>

Health and Wellbeing

Ambition

We need Health and Social Care to have a better understanding of complex support needs

Legal Guidance

The **Equality Act 2010** offers protection for people with disabilities and their carers, to ensure they are not discriminated against. Health & social care professionals need to ensure that they are working within their professional codes of conduct and meeting their competencies. They should not work in an area that is beyond their capabilities and means they should not act beyond their scope and practice. Education and training is necessary for professionals to better understand complex support needs. Advocacy organisations and specialist charities can highlight and promote the lived experience of individuals and their carers with complex support needs.

Health & social care professionals need to ensure that they are working within their professional codes of conduct and meeting their competencies. They are required to keep up with continuing professional development (CPD). They should not work in an area that is beyond their capabilities and means they should not act beyond their scope and practice.

Practical Support

The following document is designed for nurses working with individuals who have learning disabilities. It provides an overview of what needs to be considered by a professional in supporting someone from a holistic perspective.

http://www.complexneeds.org.uk/modules/Module-4.1-Working-with-other-professionals/All/downloads/m13p040b/meeting_health_needs_people_with_ld.pdf

This report highlights the need for increased understanding around children and their complex support needs.

<https://councilfordisabledchildren.org.uk/sites/default/files/field/attachment/Data%20Report.pdf>

Ambition

I hope my daughter has an occupation, she is healthy, happy, loved and has support to do as she wishes... she has her dream job

Legal Guidance

The **Equality Act 2010** promotes inclusion with people with disabilities. For instance by ensuring employers offer reasonable adjustments so disabled people can become part of the workforce.

The use of a personal budget could assist an individual with accessing work, by providing a personal assistant.

A person may be entitled to Access to Work grants to support paid work.

If you are entitled to an Access to work grant:

“You’ll be offered support based on your needs. This may include a grant to help cover the costs of practical support in the workplace, or getting to and from work.

The grant can help pay for items or services you need, including:

- adaptations to the equipment you use
- special equipment or software
- British Sign Language interpreters and video relay service support, lip speakers or note takers
- adaptations to your vehicle so you can get to work
- taxi fares to work or a support worker if you cannot use public transport
- a support worker or job coach to help you in your workplace
- a support service if you have a mental health condition
- disability awareness training for your colleagues
- the cost of moving your equipment if you change location or job”.

Practical Support

Disability Rights UK Factsheet (Disability Rights UK)

<https://www.disabilityrightsuk.org/access-work>

The Equality Act – protects discriminatory practice for disabled people. Reasonable adjustments need to be made by employers.

Access to work can be supported if you have a disability.

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

<https://www.gov.uk/access-to-work/what-youll-get>

<https://www.disabilityrightsuk.org/access-work>

Specialist Employment support to work to discover wants, skills and finding employment - Remploy

<https://www.remploy.co.uk/about-us/our-business>

Ambition

I want somewhere to meet up in the winter in the evening so I don't feel so isolated

Legal Guidance

As an adult under the **Care Act 2014** if the criterion is met and this is an identified need this could be facilitated in the plan. There is a growing awareness of the isolation that can be experienced by disabled people.

The Red Cross is part of the **Jo Cox Commission on Loneliness** where MPs, policy makers and 13 leading organisations have come together to expose the growing crisis of loneliness and find ways to overcome it.

Practical Support

There is an informative blog from Scope that discusses the feelings around evening isolation:

<https://community.scope.org.uk/discussion/37541/disability-and-social-isolation>

Red Cross blog

<http://blogs.redcross.org.uk/health/2017/07/disabled-people-loneliness-common/>

Jo Cox Commission on Loneliness <https://www.jocoxloneliness.org>

Ambition

We need preventative health services

Legal Guidance

In line with the **Care Act 2014**, needs that are well supported with continuity of care through person-centred planning should minimise reliance on reactive and emergency services. There is still some way to go for the NHS not to be a reactive service. However with the concept of person-centered care planning this should be evolving and is very much on the current agenda for the NHS.

Practical Support

Delivering better services for people with long-term conditions (The King's fund)

https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/delivering-better-services-for-people-with-long-term-conditions.pdf