

Social care services for people with arthritis and musculoskeletal conditions

Social care services are a key form of support that can enable people with arthritis and musculoskeletal conditions to maintain their quality of life.

Arthritis Research UK is committed to ensuring that people with arthritis and musculoskeletal conditions have timely access to a fair and equitable social care system. We recommend that:

- The Department of Health should publish *Improving choices for care: a strategic research initiative on implementation of the Care Act (2014)* within 2017.
- The Department of Health and the Department of Communities and Local Government should work with their partners across social care to conduct an evaluation of the information and advice duty, and local authority duties to meet need, within the Care Act (2014).
- Local authorities should fulfil their duties set out in the Care Act (2014) to provide accurate, timely information and advice on care and support services to support people with arthritis and musculoskeletal conditions.
- The Adult Social Care Outcomes Framework (ASCOF) should contain measures to assess the quality of life outcomes of people with physical health conditions.
- Local authorities should ensure that their local planning documents, including STPs, JSNAs and JHWSs, capture the social care needs of people with arthritis, and plan for the provision of social care services for people with arthritis, stratified by level of need.

1. What is adult social care?

The Care Act (2014) sets out a definition of adult social care as that which '*includes all forms of personal care and other practical assistance for individuals, who by reason of age, illness, disability, pregnancy, childbirth, dependence on drugs and alcohol, or any other similar circumstances are in need of such care and other assistance*'.¹ It encompasses personal care and practical support for people with physical or learning disabilities, or a physical or mental illness, and support for those that care for them.² Many people with arthritis and musculoskeletal conditions have social care needs or are in receipt of social care services.

This policy position considers social care services for adults (those aged 18 and over) in England. It is focused on people with ongoing social care needs, rather than short-term social care services such as reablement.

Formal care services are the most common type of care services, including home care (such as care workers), day care and residential care.ⁱ These services are funded by upper tier county councils and unitary authorities or by user contributions (self-funders).^{3,4} Adult social care makes up 30-35% of local authority budgets that have adult social care responsibilities and is the largest area of spending for many.⁵ Total spending in local authorities on adult social care services was £19.6 billion in 2015/16.⁶

Informal care includes assistance with personal care, practical help and the coordination of formal services. It is unpaid and provided by family, friends and neighbours and makes up much of social care.⁷ The value of informal caring was estimated to be £132 billion in 2015.⁸ Its value is almost that of the whole of government spending on health and social care (approximately £134 billion).

People can access a mix of both formal and informal care when using services to meet their social care needs.

2. Key organisations involved in social care

Adult social care services overlap with a broad range of other service sectors including housing, welfare and benefits, health and leisure and wellbeing (see diagram in **Annex A**). Several bodies and organisations are involved in different ways:

Department of Health: The Department of Health provides oversight of the entire health and social care system and has responsibility for developing policy related to social care. It aims to develop a system of social care that provides care for those who need it and helps people stay in their homes and maintain independence.⁹

NHS: The NHS has a role in providing some aspects of social care including counselling and therapies, occupational therapy and equipment, district nursing and continuing health care.¹⁰

Care Quality Commission (CQC): The CQC is the independent regulator for health and adult social care in England. The CQC ensures health and social care services provide people with safe, effective, compassionate, high-quality care and encourages care services to improve.¹¹

National Institute for Health and Care Excellence (NICE): NICE works across health and social care to improve outcomes for people using the NHS and other public health and social care services. It develops evidence-based guidance and advice for health and social care practitioners; quality standards and performance metrics for those providing and commissioning health, public health and social care services; and provides information services for practitioners and managers across the spectrum of health and social care.¹²

Department for Communities and Local Government (DCLG): DCLG is the government department responsible for giving more power to local people, so that they can shape what happens in their area. It has oversight of local government spending.¹³

Local authorities: Local authorities assess the needs of their local population. They provide or commission out to independent contractors, a number of social care services including day care, meals, safeguarding, care homes, home care services, supported living and home adaptations. They also provide leisure and wellbeing activities to tackle isolation such as

ⁱ Home care includes help with personal tasks in an adult's own home, or with shopping and leisure activities; day care gives opportunities to socialise away from home and respite for informal carers; residential care gives 24-hour support in a residential setting, which may include nursing care from qualified nurses.



community centres, transport services and sports facilities.¹⁴ Local authorities have duties under the Care Act (2014) (see section 4).

Health and Wellbeing Boards (HWBs): HWBs are formal committees within local authorities, whose purpose is to promote greater integration and partnership between key local actors in health and social care.¹⁵ Boards assess their local communities' needs, set priorities and encourage collaborative commissioning across health and social care to improve the health and wellbeing of their local populations.¹⁶

The Association of Directors of Adult Social Care Services (ADASS): ADASS is a membership body and a charity. Its purpose is to further comprehensive, equitable social policies and plans which reflect and shape the economic and social environment of the times; further the interests of those who need social care services regardless of their background and status; and promote high standards of social care services.¹⁷

The Local Government Association (LGA): The LGA works on behalf of councils to ensure that local government has a strong, credible voice with national government. Membership includes 349 English councils, 31 fire authorities, 10 national parks and one town council.¹⁸

3. Social care services used by people with arthritis and musculoskeletal conditions

A diverse range of adult social care services are offered by local authorities (see Annex A). However, there is very little specific data about the services that people with musculoskeletal conditions access, or those that are provided, at either a local or national level.

Work undertaken by Revealing Realities¹⁹ indicates that social care is an area of unmet need for people with arthritis, particularly in home services such as aids and adaptations.²⁰ Work conducted by the National Rheumatoid Arthritis Society (NRAS) also indicates that the burden of social care for people with rheumatoid arthritis is often met by family and friends.²¹

To understand what social care services people with arthritis access, Arthritis Research UK undertook a pilot data gathering exercise. Social care services accessed by people with musculoskeletal conditions included: aids and adaptations; occupational therapy and equipment; informal care from family and friends; care services; supported living and day care services.

Other existing social care services that may be used by people with arthritis include occupational therapy services and equipment; meals on wheels; care homes; transition from children's services; and reablement services.

4. Social Care Policy

The Care Act (2014) represents the most significant reform of care and support in more than 60 years.²² The Act puts several new duties on local authorities and makes other duties clearer.²³ Those of particular importance to people with arthritis and musculoskeletal conditions are:

- **The wellbeing principle:** local authorities have a duty to promote wellbeing when providing care and support for adults and carers.²⁴
- **Prevention duty:** local authorities have a duty to provide or arrange for services which will reduce, prevent or delay care and support needs of adults and carers.²⁵



- **Information and advice duty:** 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 carers.²⁶
- **Duty to assess for needs:** where it appears that an adult or carer may have a care and support need, local authorities have a duty to carry out a needs assessment. This duty applies regardless of the level of need or the adult's or carer's financial resources.²⁷
- **Duty to meet needs:** a local authority must meet the needs of an adult, whose care and support needs meet eligibility criteria.

There are two types of duty in the Care Act (2014), the first applies in relation to whole populations (such as the prevention duty; and the information and advice duty). The second applies in relation to individuals and are individual rights under the care act (e.g. the duty to assess for needs; and the duty to meet needs).

The Care Act (2014) is supported by Regulations and Guidance which outline the responsibilities of local authorities in relation to social care, and guidance on how to identify needs:

Care and support (preventing needs for care and support) regulations (2014): These Regulations, which sit under the Care Act (2014) stipulate that local authorities must provide 'community equipment' (aids and minor adaptations) of less than £1000 free of charge to people with eligible care and support needs.²⁸

Care and Support (eligibility criteria) Regulations (2015) and Care and Support Statutory Guidance (2017): To access care and support, an adult or carer must be found to have care and support needs.ⁱⁱ A person is considered eligible if they are unable to do two or more specified outcomes and being unable to do so has a significant impact on their wellbeing.

The Care Act (2014), and its supporting documents, set out a clear framework for assessing needs, including determining eligibility.

- **A needs assessment:** identifies if an adult has a care and support need and if those needs are eligible for local authority support.
- **A financial assessment:** determines whether the adult should fully or partially fund those services or if the local authority should contribute or fully fund the services. (see Annex B).

These assessments can be carried out simultaneously. However, neither should influence the outcome of the other.²⁹

If some of an adult's needs meet the eligibility criteria, local authorities must consider how those needs will be met; ascertain whether an adult wants to have those needs met by the local authority; and establish that the adult in need of care and support services is an ordinary residentⁱⁱⁱ of that local authority.

If a local authority determines that a person's needs are not eligible for local authority care and support, they must provide a written explanation that is personalised and accessible to that person. Local authorities are also required to provide advice and information on what services are available in the community that can support each person in meeting their needs.³⁰ Local authorities must also signpost those whose needs have been deemed

ⁱⁱ or support needs for carers

ⁱⁱⁱ In most cases, this means the place a person normally lives. In certain cases this is slightly more complicated e.g. Students; people living in care homes outside of the local authority; or prisoners.



ineligible, to information and advice about what care and support they might be able to access themselves.

Fluctuating conditions: The guidance set out by the Care Act (2014) is based on needs, rather than types of health conditions a person may have. However, it does include provisions for fluctuating needs in eligibility and assessment guidance, which is relevant to people with some forms of arthritis: 'Where the level of an adult's need fluctuates, in determining whether the adult's needs meet eligibility criteria, the local authority must take into account the adult's circumstances, over such a period as it considers necessary to establish accurately the adult's level of need.'³¹

5. Evaluation and implementation of the Care Act (2014)

A number of organisations, including the Department of Health have sought to understand, and to some extent, evaluate how the Care Act (2014) is being implemented.

The Department of Health commissioned the research 'Improving choices for care: a strategic research initiative on implementation of the Care Act (2014)', in 2015. It sought to evaluate and inform implementation of the Care Act (2014). This focused on how the Care Act is being implemented locally, and how effectively it is achieving its underlying aims. This evaluation paid particular focus to prevention; carer support; personalisation, choice, control and continuity of care; planning for later life; market shaping; and a partnership approach to implementation. An underlying theme was wellbeing and how this is being promoted at local authority level.³² This research is unpublished.

Other organisations evaluating the implementation of the Care Act (2014) include Carers Trust, who published Care Act for carers: one year on lessons learned, next steps.³³ This examined how the Care Act implementation had impacted on carers and where improvements need to be made.

6. Social care data

There are a number of national data sources in adult social care, some of which are available through NHS Digital. These include:

- The Adult Social Care Survey^{iv}
- Short and Long Term (SALT) support return^v
- The Carer's Survey
- Mental Health and Learning Disability Data Set V1.1^{vi}
- Hospital Episodes Statistics (HES)^{vii}
- UNIFY2 (NHS England)^{viii 34}

These data sets capture different aspects of social care data, some of which support indicators in the Adult Social Care Outcomes Framework (ASCOF).

^{iv} A national survey commissioned by the Care Quality Commission and the Department of Health, developed to understand at a national level how well state provided services are meeting service user needs and is also used locally to inform service delivery and to monitor and develop standards.

^v A set of measures produced through consultation with stakeholders as part of a zero-based review of social care data collections, with two main sections: short and long term. It accounts for the changing context of adult social care.

^{vi} Provides timely data and presents a wide range of information about care given to users of NHS funded secondary mental health and learning disability services.

^{vii} Data warehouse containing details of all hospital admissions, outpatient appointments and A&E attendances in England.

^{viii} Gathers data around reasons why delayed transfers of care occur.



Adult Social Care Outcomes Framework (ASCOF)

The Adult Social Care Outcomes Framework (ASCOF) is used both locally and nationally to set priorities for care and support, measure progress and strengthen transparency and accountability.³⁵ ASCOF is split into four domains and contains several measures in each domain (see [Annex C](#)). Within domain one, social care related quality of life is the overarching indicator. This is underpinned by measures that consider the employment status and living situation of people in touch with secondary mental health services; and people with learning difficulties. It does not contain a measure for gathering the same information about people with a physical disability and employment status and living situations. Parity of esteem in capturing data would be invaluable.

Joint Strategic Needs Assessments (JSNAs) and Joint Health and Wellbeing Strategies

(JHWS): JSNAs and JHWSs are important local planning documents. Local authorities, alongside their Clinical Commissioning Group (CCG) and Health and Wellbeing Board (HWB), must undertake a JSNA and produce a JHWS.³⁶ JSNAs and JHWSs must take into account all the health-related needs of their population, including any social care and public health needs that may exist.

Arthritis Research UK published a report '[A fair assessment?](#)' examining how local authorities account for the needs of people with musculoskeletal conditions in JSNAs and JHWSs.³⁷ This report highlighted that many local authorities in England are failing to adequately assess the needs of people living with musculoskeletal conditions. Key findings included:

- 1 in 4 local authorities had not included the needs of people with arthritis, musculoskeletal conditions or osteoarthritis in their JSNAs. Of 152 local authorities:
- Only 55 of local authorities included osteoarthritis in their JSNAs.
- Only 58 of local authorities included back pain in their JSNAs.
- 142 of local authorities included falls, fragility fractures, bone health and osteoporosis in their JSNAs.
- 142 of JSNAs and 86 of JHWSs mention falls, fragility fractures, bone health and osteoporosis. Only one local authority included osteoarthritis in their strategy to meet local health needs

The lack of inclusion of musculoskeletal conditions in these documents suggests that opportunities to understand and address the social care needs of people with arthritis at a local level are being missed.

Sustainability and Transformation Plans (STPs): STPs are 5 year plans for the future of health and social care services in local areas. NHS organisations along with local authorities and other partners work to develop these plans, currently this is taking place in 44 areas of the country. STPs should represent a significant change in the planning of health and social care services in England.³⁸ STPs may be able to support capture of the health and social care needs of people with arthritis.



7. The future of the social care system

Changes in the demographics of the population and the ways in which public services are funded have led to a number of growing pressures on the social care system. These changes include:

- The proportion of the population aged over 65 is rising in line with rising life expectancy.³⁹
- Long-term conditions are more common in those aged over 65.⁴⁰
- Painful musculoskeletal conditions are now the largest single cause of years lived with disability (YLDs), and the third-largest cause of disability adjusted life years (DALYs) in the UK.⁴¹
- The number of people with osteoarthritis of the knee is estimated to increase from 4.7 million in 2010, to 5.4 million in 2020, reaching 6.4 million by 2035. The increase in knee osteoarthritis will be substantial in those over 65, and greatest in those over 75.⁴²
- The prevalence of people living with multimorbidity is growing.^{43,44}

These factors are leading to an increased demand for social care services, including from people with arthritis and musculoskeletal conditions. This trend is predicted to continue.⁴⁵

Integration of health and social care: Integration is an organising principle for the delivery of care that is holistic and person-centred.⁴⁶ The aim of integrated care is to address fragmentation in patient services, and enable better coordinated and continuous care, frequently for an ageing population which has increasing prevalence of chronic disease. Integration of health and social care has the potential to offer more cost-effective services in response to spending cuts; efficiency savings; demographic changes; and recognition that too many people are not getting the services they need.

Integration is taking place at a local level facilitated by HWBs and STPs.⁴⁷ A number of larger areas have already begun the process of integrating health and social care, including Greater Manchester ('Devo Manc'). The Better Care Fund (BCF) is a single, pooled, budget for health and social care service to encourage integration through closer working at the local level.⁴⁸

8. How is Arthritis Research UK involved?

Arthritis Research UK puts people with arthritis at the heart of everything we do as a charity.⁴⁹ Our long-term commitment is to prevent the onset of arthritis, develop a cure for arthritis and transform the lives of those living with arthritis. Our strategy aims to make a positive and tangible change in quality of life for people with arthritis so that they can say 'I am in control, independent and recognised'. There are a number of ways in which Arthritis Research UK is engaging with the social care sector:

Revealing Realities findings-unmet needs: In 2015 Arthritis Research UK, commissioned Revealing Realities to carry out research with people with arthritis to look at what affects their quality of life.⁵⁰ This research contributes to our knowledge base on unmet need of people with arthritis. This study focuses on important aspects of living with the chronic pain of arthritis and highlighted areas of unmet need around social care that has a significant impact on the quality of life of people with arthritis.

Aids and adaptations in the home project: Building on Revealing Realities study of unmet need, Arthritis Research UK is carrying out work to understand the way in which aids and adaptations in the home can impact on the quality of life for people with arthritis. The project will build on existing knowledge and research into unmet need of people with arthritis being



undertaken by the charity. It explores key principles and legislative duties in seeking to understand the role of local authorities in addressing need.

Arthritis Research UK's coalition working in social care:

The Care and Support Alliance (CSA): Arthritis Research UK is a member of the Care and Support Alliance which was established in 2009 as a coalition of 90 organisations, representing millions of people, to campaign for a properly funded care system alongside the millions of older people, disabled people and their carers who deserve an appropriate level of care.⁵¹

Care for Tomorrow: Arthritis Research UK has been involved in the work carried out by Independent Age calling for a commission into the future of health and social care that is:⁵²

- Independent and has cross party support.
- Looks not just one or five years into the future, but at the kind of health and care services which should exist in 20, 30 or 50 years' time.
- Listens to a wide range of voices including health professionals and people who use health and care services.

9. Recommendations

Arthritis Research UK is committed to equitable, fair and timely access to social care services for people with arthritis and musculoskeletal conditions. To facilitate this, Arthritis Research UK would like to see:

- The Department of Health should publish *Improving choices for care: a strategic research initiative on implementation of the Care Act (2014)* within 2017.
- The Department of Health and the Department of Communities and Local Government should work with their partners across social care to conduct an evaluation of the information and advice duty, and local authority duties to meet need, within the Care Act (2014).
- Local authorities should fulfil their duties set out in the Care Act (2014) to provide accurate, timely information and advice on care and support services to support people with arthritis and musculoskeletal conditions.
- The Adult Social Care Outcomes Framework (ASCOF) should contain measures to assess the quality of life outcomes of people with physical health conditions.
- Local authorities should ensure that their local planning documents, including STPs, JSNAs and JHWSs, capture the social care needs of people with arthritis, and plan for the provision of social care services for people with arthritis, stratified by level of need.

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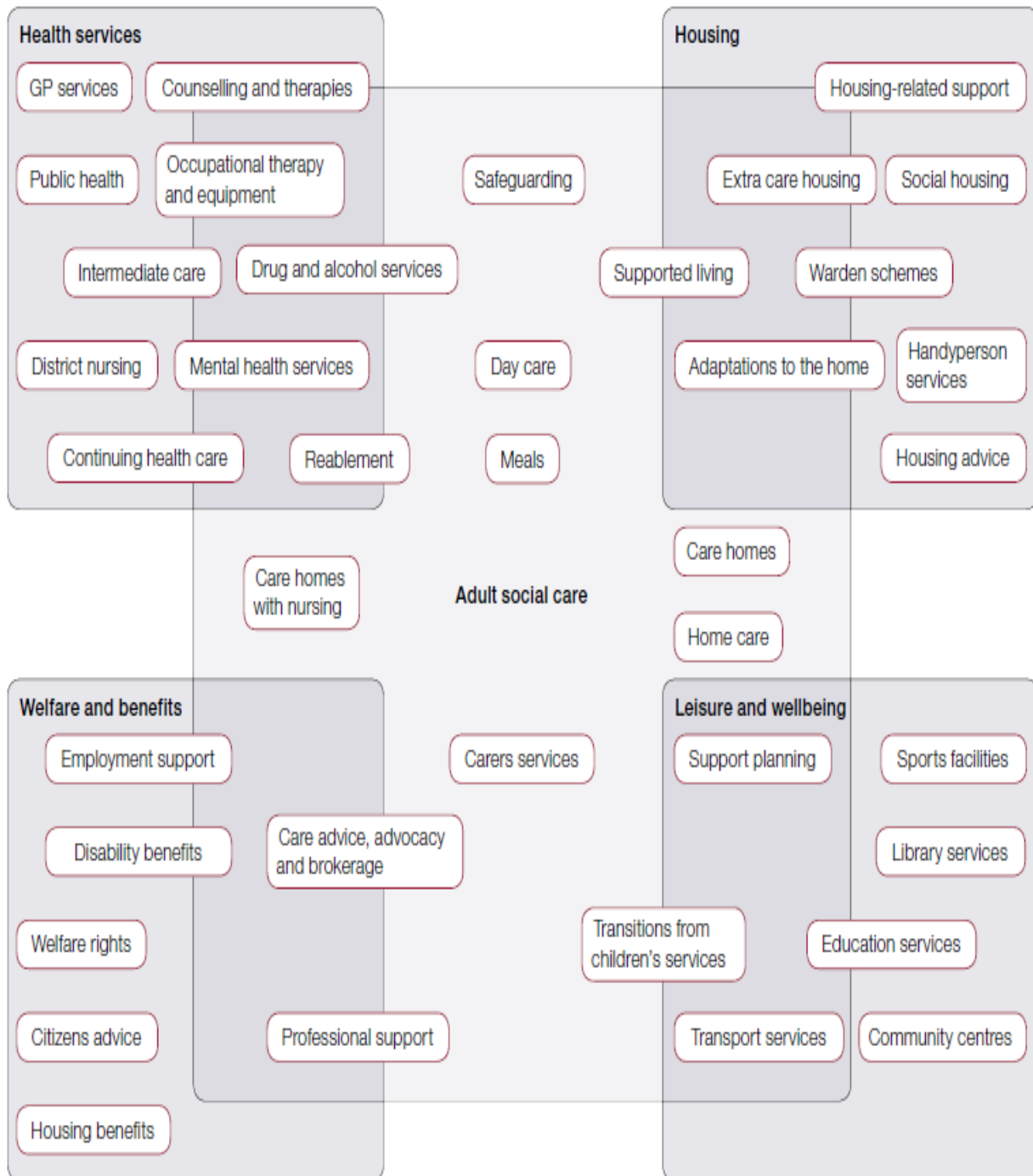
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Annexes
Annex A - Adult social care services⁵³

Adult care services and other services

How well adults' needs are met depends on all parts interacting effectively



Annex B – Assessing for needs including eligibility and financial assessments under the Care Act 2014

Under the Care Act (2014) there are two kinds of assessment:

- **Needs Assessments** identify needs of individuals and how those needs might be met, including whether they are eligible for the local authority to meet them.
- **Financial Assessments** determine who pays for an individual's care and support needs, whether that is the individual themselves or the local authority or a combination of both parties.

1. Needs Assessments determine if an adult has a care and support need. Local authorities must carry out assessment regardless of the level of need an adult has. Assessments should be holistic and person centered and they represent a critical intervention in their own right. They include an assessment of:

- The impact of an adult's needs for care and support;
- The outcomes an adult wishes to achieve in day to day life;
- Whether, and if so, to what extent, the provision of care and support would contribute to the achievement of outcomes.

Needs assessments must include any people an adult requests to be part of the process including carers. Assessments can be done face-to-face; as part of a joint assessment by relevant agencies; or as part of a combined assessment alongside a carer.

Assessments should be appropriate and proportionate accounting for:

- A person's wishes and preferences and desired outcomes;
- Severity and overall extent of a person's needs;
- The potential fluctuation of a person's needs.⁵⁴

1a. Determining eligibility for care and support requires consideration of: whether an adult has a physical or mental impairment; whether their impairment is preventing them from being able to achieve specific outcomes; and whether being unable to achieve these outcomes is detrimentally impacting on their wellbeing. This makes up how local authorities assess and determine eligibility.

A person is considered unable to achieve a specified outcome if:

- It cannot be achieved without assistance;
- Achieving an outcome without assistance endangers, or is likely to endanger, the health and safety of the adult, or others;
- An outcome can be achieved without assistance but takes significantly longer than would normally be expected.⁵⁵

Outcomes are:

- Managing and maintaining nutrition;
- Maintaining personal hygiene;
- Managing toilet needs;
- Being appropriately clothed;
- Being able to make use of an 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;
- Carrying out caring responsibilities the adult has for a child. ^{56,57}

2. A financial assessment gives local authorities the right to charge for care and support services where appropriate. Some people will be entitled to free care, and others will be means tested for financial support.

The 'upper capital limit' determines whether a person is entitled to some or whole financial support for care and support. The 'upper capital limit' for care given in a residential care home setting is £23,250. Anyone with assets and capital below this level can seek means tested support. Local authorities may also provide financial assistance to people above this level at the local authority's discretion

The 'lower capital limit' in a care home setting is £14,250. People with income below this level do not have to contribute anything to the cost of their care and support. For care and support arranged outside of a care home setting, local authorities can choose to contribute towards the cost of care even when a person has capital assets of more than £14,250.⁵⁸

There are certain kinds of care and support which must be arranged for free, regardless of a person's financial assessment. These include:

- Intermediate care, including reablement care, which must be provided free of charge for up to 6 weeks;
- Community equipment (aids and minor adaptations);
- Care and support provided to people with Cheuzfeldt-Jacob Disease;
- After care services and support provided under section 117 of the Mental Health Act (1983);
- Any service or part of a service which the NHS contribution is under a duty to provide including continuing health care and the NHS contribution to registered nursing care;
- Aids must be provided free of charge whether provided to meet or prevent/delay needs. A minor adaptation is one costing £1000 or less.



Annex C – The Adult Social Care Outcomes Framework (ASCOf)⁵⁹

Domain One: Ensuring quality of life for people with care and support needs

Overarching Measure: 1a. Social care-related quality of life

People manage their own support as much as they wish, so that they are in control of what, how and when support is delivered to meet their needs

1B. Proportion of people who use services who have control over their daily lives

1C. Proportion of people using social care who receive self-directed support, and those receiving direct payments

Carers can balance their caring roles and maintain their desired quality of life

1D. Carer-reported quality of life

People are able to find employment when they want, maintain a family and social life, and contribute to community life, and avoid loneliness or isolation

1E. Proportion of adults with a learning disability in paid employment

1F. Proportion of adults in contact with secondary mental health services in paid employment

1G. Proportion of adults with a learning disability who live in their own home or with their family

1H. Proportion of adults in contact with secondary mental health services living independently, with or without support

1I. Proportion of people who use services and their carers, who reported that they had as much social contact as they would like

Domain Two: Delaying and reducing the need for care and support

Overarching Measure: 2A. Permanent admissions to residential and nursing care homes per 100,000 populations

Everybody has the opportunity to have the best health and wellbeing throughout their life, and can access support and information to help them manage their care needs

Earlier diagnosis, intervention and reablement means that people and their carers are less dependent on intensive services

2B. Proportion of older people (65 and over) who were still at home 91 days after discharge from hospital into reablement/rehabilitation services

2D. The outcome of short-term services: sequel to services

Placeholder 2E: The effectiveness of reablement services

When people develop care needs, the support they receive takes place in the most appropriate setting, and enables them to regain their independence

2C. Delayed transfers of care from hospital, and those which are attributable to adult social care

Placeholder 2F: Dementia – A measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life



Domain Three: Ensuring that people have a positive experience of care and support

Overarching Measure: People who use social care and their carers are satisfied with their experience of care and support services

3A. Overall satisfaction of people who use services with their care and support

3B. Overall satisfaction with social services of carers

Placeholder 3E: Effectiveness of integrated care

Carers feel that they are respected as equal partners throughout the care process

3C. The proportion of carers who report that they have been included or consulted in discussion about the person they care for

People know what choices are available to them locally, or what they are entitled to, and who to contact when they need help

3D. The proportion of people who use services and carers who find it easy to find information about support

People, including those involved in making decisions on social care, respect the dignity of the individual and ensure support is sensitive to the circumstances of each individual

This information can be taken from the Adult Social Care Survey and used for analysis at the local level

Domain Four: Safeguarding adults whose circumstances make them vulnerable and protecting from avoidable harm

4A. The proportion of people who use services who feel safe

Everyone enjoys physical safety and feels secure

People are free from physical and emotional abuse, harassment, disease and injuries

People are protected as far as possible from avoidable harm, disease and injuries

People are supported to plan ahead and have the freedom to manage risks the way that they wish

4B. The proportion of people who use services who say that those services have made them feel safe and secure

Placeholder 4C: Proportion of completed safeguarding referrals where people report they feel safe



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