



RESCUING SOCIAL CARE.

**RECOMMENDATIONS FROM THE SOCIALIST HEALTH ASSOCIATION
FOR POLICY ON SOCIAL CARE AND SUPPORT.**

CONTENTS

Rescuing social care – the SHA motion P3

Labour to legislate for a duty on the SoS P3

A universal system of social care and support
– a national care service P3

Care and support to meet needs P4

Care and support must be provided in ways
that promote wellbeing P4

A right to independent living. P5

Need, quality and choice P6

Free at the point of use P7

Universally provided and in the public sector P8

New models of delivery P9

Fully funded through progressive taxation P9

Service based on national and international best practice P10

Democratically run, empowering services P11

Training to nationally agreed qualifications,
career structure, pay and conditions..... P13

Giving informal carers strong rights and support,
including finances and mental health..... P14

Personal budgets (pbs) and direct payments..... P15

The wider parameters of social care P15

Appendices P16

Central Council is asked to discuss this policy document with a particular focus on 2 questions:

- **The ratio of wages recommended in Appendix 5, P21**
- **The issue of Personal Budgets and Direct Payments P15**

CALLING ON LABOUR TO RESCUE SOCIAL CARE

England's Social Care system is broken. Local Authorities faced £700,000,000 cuts in 2018-9 with £7 billion slashed since 2010. At the same time 26% fewer elderly receive support with demand growing.

People face isolation, indignity, maltreatment, neglect, barriers to inclusion and independent living. Most care is privatised with no evidence that this is reflecting user needs/wishes. Public money goes to shareholders and hedge funds as profits. Service users and families face instability as companies go bust. We are seeing staff wages, conditions and training being slashed with a turnover rate of 30+%. And there is eight million unpaid, overworked family carers, including children and the elderly, providing vital support.

At the 2019 Labour Party Annual Conference the Socialist Health Association (SHA) called on a future Labour government to legislate for a duty on the Secretary of State of Health and Social Care (SoS) to provide a universal system of social care and support based on a universal right to independent living:

- Based on need and offering choice.
- Meeting the needs of all disabled, frail and sick throughout life with robust safeguarding procedures.
- Free at the point of use, universally provided, fully funded through progressive taxation
- Subject to national standards based on Human Rights, choice, dignity and respect for all, complying with the UN Rights of persons with disabilities, including Articles on Independent Living (19) Highest Attainable Health (25) and Education (24).
- Democratically run services, delivered through local public bodies working co-productively together with users and carers.
- Training to nationally agreed qualifications, career structure, pay and conditions.
- Gives informal carers strong rights and support, including finances and mental health.

The SHA also calls for a future Labour Government to establish a taskforce involving users and carers/Trade Unions/relevant organisations to deliver the above, including an independent advocate system, and national independent living support service (NILS). The taskforce would explore the possibility of a NILS which would include a central organisation supporting cooperative services run by disabled people.

A UNIVERSAL SYSTEM OF SOCIAL CARE AND SUPPORT – A NATIONAL CARE SERVICE

The SHA does not recommend that a National Care Service (NCS) merges NHS and Social Care centrally.

We need a National Care Service that ensures care coalesces around the person in response to their individual needs and wishes. We think that the ideologies and aims of the two services are so different that coordinated funding and aligned organisations will offer the best service to people.

This requires:

- Joint central planning
- Long-term agreed funding
- Locally constructed arrangements that are suitable for the ecology of each place. These need to demonstrate that they provide care and support that meets the variable and varying needs of people.

The social care element of a right to independent living should be delivered locally in co-production

with disabled people, service users and informal carers etc. It will be provided based on need, not profit, and will not be means tested. It will be independent of, but sit alongside, the NHS and will be funded from direct taxation.

Independent living for people living with long term conditions, the frail, service users and the disabled should be a right where this is achievable, taking safety of self or others, and compassion into account. We see this varying through an individual's life.

CARE AND SUPPORT TO MEET NEEDS

We believe that the personal social care that an individual and their carers receive must be used in its broadest sense to refer to all individual supports required by the individual to meet the needs set out below. This may include individual behavioural support, counselling, safeguarding support, advice and prompting, skills training and so on which is required over and above that available to the wider public

Everyone should have the right to receive social care and support that takes full account of the individual's need for:

- personal dignity.
- physical / mental health / emotional well-being.
- protection from abuse and neglect.
- control over day-to-day life including through the nature of care provided.
- participation in work, education, training or recreation.
- social and economic well-being.
- domestic, family and personal relationships.
- suitability of living accommodation.
- the adult's contribution to society.
- the need to avoid deterioration in any of these areas.

The importance of these issues will differ for everyone, but assessments must cover all these elements, with no hierarchy of importance. The nature of care and support required to meet these needs, and the skills required of staff, will be equally varied. For instance, some individuals will require support from staff with appropriate skills and qualifications to respond to fluctuating or complex medical needs, often including issues of mental capacity or end-of-life care, and these staff will need to be closely aligned with NHS services. Others will require staff with the skills to support them through a mental health crisis, while some will need support with challenging behaviour, or staff who have the skills to support them through a rehabilitation programme or to develop skills for everyday living. Some people will need help to manage complex personal or other relationships, including safeguarding issues. Others simply need support staff who will follow specific requests for support with everyday living, or to engage with work, education or recreation.

CARE AND SUPPORT MUST BE PROVIDED IN WAYS THAT PROMOTE WELLBEING

The principles of well-being include:

- initial assumption that the 'individual' is best placed to judge well-being
- effective advocacy and strong safeguards for those who lack capacity to make their own decisions or express their own individual's views, wishes and feelings.
- taking into account all the individual's circumstances (and non-discriminatory in terms of stereotyping etc).

- individual participating (with support if needs be) as fully as possible in decisions about themselves.
- a balance between the individual's well-being and that of any friends or relatives involved in their care.
- the need to protect people from abuse and neglect through effective safeguarding procedures
- any restrictions should be kept to the minimum necessary.

A RIGHT TO INDEPENDENT LIVING.

Current approaches, despite the Care Act, tend towards the patriarchal, offering people what the system wants them to have. Independence can be curtailed by social attitudes and by social structures, such as architecture and other kinds of infrastructure. Independence can also be enhanced, and other groups have highlighted how this can be achieved. One example from a care home, was simply painting toilet seats and door frames red – the last colour which impacts on people with dementia.

Independent living must respond to the wide spectrum of needs of people requiring social care. A number of people of all ages are well able to recognise and articulate their own needs for care and support and have the skills to design their own support service. Others are in a hugely different position and need services that have been designed by others to meet their needs. They want carers to be available when they need support, to have the skills to provide the personal or other care they need and care that is considerate, respectful, personalised and affords dignity.

The SHA recognises the Social Model of Disability definition which recognised that economic, social, cultural, physical and political barriers work to disable people and exclude those with impairments or long-term health conditions.

We use the term disabled people to include those with physical, cognitive and sensory impairments, people with learning difficulties; people who are neuro-diverse; deaf people, deafened, hard of hearing people, mental health system survivors/ people who experience mental distress, and others. It applies to disabled people of all ages – from birth to death.

The principle of independent living can be positively applied as appropriate to people with an impairment, including older people with many illnesses such as physical problems and dementia. How independent living is applied, given the caveats we mention, will vary for each person with their own unique spectrum of assets and restrictions. Where possible, taking safety into account, people should have the choice to receive care and support in their own home, in supported accommodation or in a residential setting where this meets their needs. Whatever their impairment or need, people should be supported to have maximum control and as fulfilling and dignified a life as possible.

We are aware that the principle of independent living and 'maximising independence' has sometimes been misused to limit services. Maximising independence must always be seen as providing the support an individual needs to live a fulfilling life.

Capacity to take decisions is a complex area subject to detailed legislation, case law and guidance. It bears an important connection to social care policy and will be an essential component of assessment in relation many recipients of social care including people who are unconscious following accident, stroke etc, at the end of life, people with dementia, with learning disabilities, or with active psychosis for instance.

Where someone lacks capacity to take decisions – whether major or minor - about their care or support, it is essential they have effective, skilled, advocacy support whether from close friends or family or through professional advocacy services.

Even where people have capacity to make decisions, it is essential they have access to professional advocacy services that can offer advice and guidance.

The SHA agrees with the Equality and Human Rights Commission² that the following key elements, in combination, make up a potential model for incorporating the right to independent living into domestic law:

- A. A Public Sector Inclusion Objective
- B. A qualified presumption in favour of living in the community
- C. The primacy of the views of people in need of care and support, officially, or with such support provided informally.
- D. Assessment of unmet need
- E. Enforcement and interpretation

NEED, QUALITY AND CHOICE.

The Care Act offers an approach that can be expanded. Largely because austerity has made fulfilling the requirements of Act so difficult, the Act is routinely ignored.

Personalised care and support:

There should be a range of care and support services available in line with an individual support plan and expected outcomes that are tailored to individual wishes, personal circumstances and needs. Outcomes should take account of safety and safeguarding issues as well as individual needs and aspirations. Care and support will be designed and delivered around an individual's needs through a qualified and regulated practitioner, whilst the responsibility for managing budgets will lie with the local authority or NHS. Additional financial and practical support will also be available to family carers.

Services available in every locality should include flexible and responsive community service support throughout the week, night sitting and night visiting, appropriate equipment, aids and adaptations to assist daily living, skilled nursing, community physiotherapy, occupational therapy, chiropody, speech and language therapy and help from a dietician, bathing services, rehabilitation, skills development, mental health support, behavioural support and palliative care

People living in a communal setting, and their family carers where appropriate, should also have the right to a say in how the communal setting is organised and run.

Quality

Staff must be well supervised by managers with appropriate skills and expertise to manage any specialist care needs, and the service must be able to demonstrate that it is meeting expected outcomes, including needs, and aspirations.

High quality personal care and a holistic approach.

Skills of carers need to be matched to the needs of people they support. Where staff simply follow instructions given by competent service users, the level of skill required may not be great. However, many people require much more skilled, professional support.

Many frail elderly people at end of life and people with complex health conditions who until recent

times would have received nursing care in hospital are now supported at home or in care homes, most often by staff with no formal qualifications, minimal training and on very low wages, working for services whose primary aim is to make profit. Personal care is currently regarded as unskilled work. In these circumstances carers could need a level of nursing skills which would allow them to recognise and respond to a wide range of health conditions and detect changes in health status.

Other people need staff with a wide range of skills, not least the ability to use initiative to deliver good quality holistic support. For instance, a young woman with learning disabilities and physical impairments may have problems with daily living skills and accessing community facilities as well as with personal hygiene. Staff should be helping her to understand the importance of keeping herself clean and the impact of unpleasant odours on her social contacts. Staff also need to teach skills to allow people to manage their own personal care effectively, and it may take months of active intervention to achieve this. It's not feasible to separate out the intimate personal care elements from the ongoing support, including support to develop a range of skills, that she needs through the day. She needs to get consistent and ongoing support from the same staff who plan menus and go shopping with her, go with her to college, help her learn to cross the road safely and help her manage her money, get to the local dance night and keep herself safe from the predatory 'friend' who insists she's his girlfriend. She needs staff who can deliver holistic care and support; staff who have a sound understanding of nutrition, motivation, safeguarding and skills development as well as personal care.

The skills of professional carers need to be wide and can merge into nursing skills.

We need to enhance the competency of professional carers where complex personal, nursing and social care come together for many clients. Those responsible for delivering such care should be highly trained and well rewarded and be equally at ease in domestic and more managed care settings. **Dual registration with nursing would be a necessary first step.** There should be easy access to formal nursing skills when needed.

Safeguarding

Numerous examples of abuse and neglect within the care system have highlighted the need for robust safeguarding procedures, and these must be preserved and strengthened through further involvement of service users and family carers.

FREE AT THE POINT OF USE

The main priority is to work towards care which is free at the point of use for all. This will result in an end to means testing.

The 2019 Labour General Election manifesto made a commitment to providing free personal care for users who were over 65yrs and to place a cap on lifetime payments. This is a welcome step forward which should be extended to other age groups with a similar range of needs.

Discriminating against people under 65 which, so far as social care provision is concerned, relates mainly to disabled people of working age.

Scotland is offering free personal care now. It has resulted in an increase in demand for services particularly for home domiciliary care. This Scottish experience shows that any plans need to take into account the likelihood of addressing suppressed need due to the costs arising from a means tested service.

UNIVERSALLY PROVIDED AND IN THE PUBLIC SECTOR

We expect quality to be equitable across the country, with clear standards that every council needs to meet. These standards need to be compatible with UN Standards.

SHA believes that personal care services should be provided overwhelmingly by public bodies – though with a completely different approach to service user and family carer involvement as set out in this document. The market in social care has resulted in catastrophic decline, with hopelessly inadequate regulation, de-professionalised staffing, plummeting standards with both public and private money syphoned into corporate profits, often via tax havens.

The Covid-19 epidemic has further demonstrated the limitations of this model which, in the times of crisis, is only sustainable within a public service framework. Tens of thousands of social care staff were expected to care for very frail people, including many with suspected Covid-19, moving from one vulnerable person to the next with little or no PPE.

Social care must be returned to delivery by public bodies. We do not believe that voluntary sector and not-for-profit organisations should be expected to compete with corporates in a market for services to vulnerable people.

Bringing services back into the public sector.

We see this as a prerequisite to fair, efficient services. However, nationalising social care will not, of itself, result in the sort of holistic services that are needed. Other aspects of our recommendations will make those possible. They all must be taken together.

Councils need to be ready to do this and increasing local authority capacity will be a priority.

Increasing funding would be an essential starting point alongside appointing Directors and managers who have sound experience of planning, delivering and managing effective care and support services.

Bringing care back into the public sector

This may be relatively easy. Councils could bring social care contracts in-house once they have reached their expiry date. Domiciliary care provision is the obvious place to start not least because it is the sectors that delivers the most care. The development of in-house expertise at senior and middle-management levels will be essential, though in some areas there may be scope to share management expertise (and costs) with adjacent authorities. Costs currently arising from the procurement and contracting will be eliminated and transferred to the direct care service.

Bringing residential care into the public sector

Real progress on this will almost certainly require action by central government, which could involve legislation to allow compulsory purchase with compensation of existing homes as well as capital funds to develop new supported accommodation. There are well-established legal and financial processes for this task. Over the longer term, rental charges will repay the capital outlay. As above, savings in contract costs and cyclical procurement and monitoring costs should mean that in-sourcing for comparable resources is cost-neutral.

The position of the voluntary / third sector.

Public bodies need to be able to use the voluntary sector to develop and run innovative services, or services that meet the specific needs of communities. These services should be grant-funded, not run through commercial contracts to provide specific services. They should be developed in close liaison with local authorities, with one aim being for local authorities to learn from these innovative services and adapt to incorporate the best elements into public services.

NEW MODELS OF DELIVERY – SOCIAL, MUTUAL AND CO-OPERATIVE?

The evidence is that what people want from social care is small-scale provision and personalised care. A good example might be extra care homes, which allow for both care and independence, in a supportive and personalised environment. This modernised model of care delivery, small scale and personalised, could be provided by small council-owned care homes and council-owned supported living provider organisations, or if the council did not have the capacity, by alternative non-profit forms of ownership in line with the Labour Party consultation report *Alternative Models of Ownership*, published in 2017. It advocates, as well as nationalisation and municipal ownership, various forms of community-owned and worker-owned non-profit social enterprises, including co-operatives.

At the same time, the voluntary sector and not-for-profit organisations have made a major contribution in developing innovative and specialised services that are highly valued by service users. We want to see this role continued. There is scope for this through the grant-funding powers of local government (which was the norm for many years prior to the huge expansion of the market in social care).

The move in the past two-to-three decades from grant-funding to commercial contracts for services has been hugely detrimental to the ability of voluntary sector organisations to explore new innovative approaches and develop responsive services. We want to see this role restored, with voluntary and not for profit agencies grant-funded to provide ongoing action research in partnership with local authorities, leading to developments that are also used to inform mainstream services. We envisage a greatly expanded and ongoing role for such action-research.

FULLY FUNDED THROUGH PROGRESSIVE TAXATION

We propose that Social Care should be fully funded and by which we mean:

- Everyone gets the Social Care they need
- The system is universal and free with no means-testing.
- People who need Social Care get entitlements that are sufficient to enable them to live as equal citizens
- Social Care staff are paid fairly, with recognition of the skills and experience required for good personal care.
- The essential role of family and the wider community is recognised, respected and supported
- Social Care is funded by progressive taxation, on the same basis as other public services, not linked to some hypothecated income stream, which may or may not be adequate over the long-term
- The system is subject to regular review and is accountable to all users, families, staff and the wider communities they serve and can be monitored against human rights standards

It is perfectly possible for the UK to fully fund social care; in fact, the failure to invest in social care creates multiple problems, which have significant social and economic costs. Most importantly the failure to fully fund social care is a failure to recognise the human rights of the people who need support, and are formal or informal users, carers, or clients etc. under the current system, and people in need who have been refused.

We need a new way of thinking about what we mean by a fully funded social care system. Instead of treating social care as some kind of necessary evil, whose costs must be controlled whatever the human price, we must develop an ecological model that seeks to find the right balance of investment in social care to ensure all of the following objectives:

- Maximise the contribution by people with long term health conditions, disabled people to community life, with full protection for independent living as appropriate.
- Support the integrity and value of family life, enabling mutual support and a good life for people who are disabled and for family members ('carers')
- Foster accessible and inclusive communities that can welcome and support each other and where every citizen can find role of value
- Pay Social Care staff decent wages, acknowledging their value and the value of those they support
- Rebalance social care so that a priority is given to services that support citizen and community development.
- Guarantee parity and cooperation between social care and other public services, ensure all public services are as accessible as possible to the whole community.
- Ensure Social Care is valued and understood by the whole community and there is widespread support for ensuring sustainable investment in it.

To achieve these standards, we need to recognise the massive under-investment that has taken place under austerity with the longer-term aim of investing 2% of GDP in social care.

Social care and support makes a significant contribution to the local economy. It has been calculated that the provision of adult social care in England contributes through Gross Value Added at least three times its cost to local authority budgets. Social care and support is a large employer, increasing life skills across a wide population, cementing community links and fostering citizen contribution. Social care enriches community life for everyone.

Unison estimated that 650,000 new social care staff will be needed by 2033 [reported by Unison to SERTUC, 2018). As technology makes increasing numbers of jobs redundant it should be a priority to make adult social care and support a positive employment opportunity with decent wages, mandatory training and development opportunities.

The current exceptionally low wages, limited training and career development are vital factors that a local economic as well as social strategy should redress, with national backing. Social Care provision can often enable those in receipt of its services and community groups to grow their contribution to the local community.

A SERVICE BASED ON NATIONAL AND INTERNATIONAL BEST PRACTICE.

The SHA believes that we need to replace our present model of limited, means tested care towards one that aspires to best international standards.

The United Nations Rights of Persons with Disabilities sets an important benchmark which we should aim to achieve. Community services and facilities for the general population must be available on an equal basis to persons with disabilities if appropriate, safe and compassionate. Many people could take positive advantage from the rights set out the importance of living independently and being included in the community (Article 19). This involves the opportunity to make choices, enjoying life on parity with other citizens. Public services such as education (Article 24) and health (Article 25) should be delivered at the highest attainable standard without discrimination based on disability or long-term health conditions etc.

DEMOCRATICALLY RUN, EMPOWERING SERVICES

We expect that all services offering social care and support will:

- Institutionalise or support active citizenship where at all possible.
- Incorporate accountability to local people
- Invest in community
- Collaborate with each other and with other parts of the statutory and voluntary sectors
- Share intellectual property
- Strengthen leadership within the communities it serves

The Labour Party has developed the policy of participation further in the report *From Paternalism to Participation: Putting civil society at the heart of national renewal.*ⁱ

Labour wants people to have a bigger say over the public decisions and the public services that affect them, with more direct accountability to service users where possible.

(It) will promote collaborative decision making, encouraging public service providers to involve their service users in taking decisions about how those services are run, the outcomes they are working towards, and the support they offer. This cannot be limited to consultation alone – people need the power to assert their voice when those in power refuse to listen, and civil society has an important role in acting as their advocates and champions. (p10)

This policy should apply to all public and service providing bodies. There needs to be effective participation by service users and service workers – by citizens - in strategic policy-making at all levels of decision making and not just in service delivery at neighbourhood level. This would open the door to popular challenge to dominant policies and power structures which sustain social injustices.

Every social care service should have service users and (where appropriate) family carers involvement at its heart. The form this takes will differ according to the service and local wishes. However, the principle must be that there exist strong pathways both for individuals to have their views listened to and acted on, and for service users to have a say in the management and monitoring of their service.

Social workers or community development workers have a critical role in working with local neighbourhoods to make them more welcoming places and to reduce the risk of crisis by linking people together and encouraging inclusion.

We need to recognise that most care and support is provided by family and friends and that one purpose of social care is to enhance citizenship and to strengthen family and community life. Effective social work and other professional roles are best carried out in a spirit of partnership with people, enabling the innovation and community change necessary to build the kind of good society we seek. Rights to control, information, advocacy and peer support will be an essential element of good social care system.

An effective system of social care will develop local community resources and habits which are generated, owned and controlled at a local level. Good social care will be reflected in inclusive and caring communities where problems are identified and solutions created by local people. Good community development and social work or local area coordination will work to strengthen local community strengths.

Social care will need to be linked to decisions made by education, housing and health care systems - ideally at one coordinated level. Management coordination and mutual responsibility would rely on team work, standardised boundaries and shared democratic accountabilities.

Local government is a key, but not exclusive, forum where social care decisions are made. How could these policy aims be translated into practice in local government? The SHA supports a combination of representative and participatory democracy in Council and Town Halls through five inter-related reforms:

1. Council Committees with participation by the users and providers of services

Each Cabinet Portfolio service sector should establish an advisory committee comprising a group of Councillors together with representatives of service users and the workers providing the service. Sub-committees could be set up as needed. Alternatively, Councils could scrap the Cabinet model altogether and return to a Committee system, which they are legally allowed to do, again with representatives of service users and workers.

2. Participation by the users and providers of services in each Scrutiny Committee

All Scrutiny Committees can co-opt members and therefore there should also be representatives of service users and the workers providing the service on each Committee. Again, sub-committees could be set up if needed.

3. Citizen Forums

It should be a basic civic right that the Council facilitates meetings of citizens with common concerns and interests that extend beyond the boundaries of individual Ward Forums. Citizen Forums, perhaps authority-wide, would enable a vital horizontal connection between service users, workers who provide them, communities and councillors, creating a rich fabric of shared experiences, knowledge and ideas for improvement. (In Birmingham, the Council's recent launch of a monthly open 'People for Public Services: Citizen Engagement Forum' on Adult Social Care has set a positive precedent.)

4. Community Development.

Community Development (CD) is an approach that enables local people to identify the issues that matter to them and then be supported to negotiate responses and solutions to those issues, harnessing the assets and insights of the communities themselves. It thus enables local people to help set the agenda for planning, working with the statutory sector which may in addition include education, police. This is a key approach to participatory democracy.

Community Development has been shown to improve health, help tackle health inequalities, encourage positive health behaviours and be good value for money.

Every council, in conjunction with its local NHS, perhaps through its Health and Well-Being Board, should produce a Community Development (CD) strategy. This should deliver a CD presence in every ward. At the same time, there needs to be significant change in the governance of the Local Authority and the NHS to ensure that the system is responsive to the drive to democracy at local level.

5. Keep social care services local.

Local social care services must reflect local needs. Large numbers of adults with learning disabilities, autism and mental health needs as well as older people are accommodated out of area because of lack of suitable accommodation and support in the local area. These out of area placements leave people isolated from family, community and friendship networks and mean they may be particularly vulnerable to abuse and neglect. It is essential that all local authorities are required to develop local services to meet all but the most specialised needs.

6. Service user and family carer involvement in service development, management and monitoring

'Quality' can be difficult to measure in social care. Proxy measures such as staffing

qualifications and staffing levels are important but not sufficient. Current monitoring of services relies heavily on a checkbox approach and is hopelessly inadequate (as shown by numerous findings of abuse in care homes that have CQC approval).

However, service users and family carers are an invaluable source of information about service quality – they understand immediately whether staff are helpful and caring and whether staff are available when they are needed. Service users and family carers also represent huge potential resource for information about service development which should be drawn on at every level.

7. **Inclusive digital participation in policymaking**

As “*From Paternalism to Participation*” says, ‘The digital revolution offers radical opportunities to increase public accountability and participation in decision-making’ (p10). In order to make access to the policy process more accessible to all, Councils should set up digital networks to enable online participatory democracy in policymaking, like Decidim - We Decide - in Barcelona.

This is a digital platform for participatory democracy that allows citizens to make proposals, deliberate on them, promote them and collectively defend and improve them. It was used to build the strategic plan for the city of Barcelona, and to develop some prototypes of processes such as participatory budgeting. [18]

TRAINING TO NATIONALLY AGREED QUALIFICATIONS, CAREER STRUCTURE, PAY AND CONDITIONS.

There are over 20,000 different care providers in England alone and they can vary wildly in the quality of training they provide to staff. However most social care staff are given minimal and highly inadequate training; care is generally regarded as unskilled work, and this low status is reflected in exceptionally low rates of pay.

One immediate solution to this issue would be to focus on professionalisation. We need to see the government introduce a new standardised training and career development framework and scaffolding that prioritises up-skilling – and that means investment.

Domiciliary care workers often work to tight schedules that do not allow the time necessary to support clients in self-care, or to establish the relationship that is the necessary foundation of a high quality personalised service and a key factor in job satisfaction.

In Wales legislation specifies that visits must be long enough to enable appropriate care. We recommend the same legislation in England.

The SHA welcome a range of service changes being proposed by the trade union movement including the GMB and Unison. They include: -

Regulation and monitoring: In the residential care sector regulation is exceptionally weak and inadequate to the task of supporting some of the most vulnerable people in society.

The development of regulation and standards is essential to any proposals for reform. This needs to start with establishment of a social care college equivalent of the medical Royal Colleges which are independent of government and able to establish appropriate standards for services and staffing and training needs to meet social care needs across different settings.

In addition, care staff who are employed either by an individual, local authority, agency or care

home company should have an appropriate qualification as a minimum standard as an essential requirement for registration.

INFORMAL CARERS' STRONG RIGHTS AND SUPPORT.

CarersUK. have campaigned for number of improvements to enhance the status and support available for carers which the SHA supports.

Ensure that carers and their families do not suffer financial hardship as a result of caring

- Carer's Allowance, just £66.15 on 2019/20 rates, must be raised across the rest of the UK to the same level as Scotland, with equivalent increases to carer premia to ensure that those on the lowest incomes benefit. In the longer term, financial support for carers must be increased significantly.
- The earnings threshold for Carer's Allowance needs to rise year on year in line with the National Living Wage, pegged at least to the equivalent of 16 hours a week so carers do not have to choose between Carer's Allowance and staying in work.
- To auto-enrol carers in a second pension – a Carer's Pension that recognises the value of unpaid work and ensures that they do not suffer financial hardship later in life. The allowance should not end when the carer reaches pensionable age. This is a time when there is often a loss of income, and there should be a recognition of the amount of money carers of all ages save the government. The UK has one of the lowest pensions in Europe.

Health and social care services that recognise, value and support carers

- A new duty is needed on the NHS in England, Wales and Northern Ireland to identify carers and promote their health and well-being, including their own employees who are juggling work and care. Ensure that all staff are trained to know about carers and how to support carers.
- Increase identification and support through primary care.
- Ensure carers are better prepared for caring and can get support early to look after their own health and well-being with easily available advice and information as well as learning and training for carers to help them plan, prepare and provide care.

Provide funding and choice of quality services to enable carers to live their own lives and take the breaks they need

- Caring should be a choice for both family carer and the person receiving care, not a requirement.
- Increase and ring-fence funding for carers' breaks. Funding should also be transparent so carers know what they are entitled to, and ensure greater consistency in what is available.
- A choice of appropriate and good quality care must be available or carers cannot get the breaks they need for their own health and wellbeing.
- Ensure carers are able to engage in leisure as well as work alongside their caring role, if they wish to, with support to return to work alongside or after caring
- Create a new right to paid time off work to care of at least 5–10 days.
- Put in place tailored support for carers looking to return to work, including recognising the skills the carers have developed through their caring role.
- Work with employers to include carers in health and well being support at work.
- Recognise that good quality and affordable care services are an essential part of enabling carers to remain in or return to work alongside caring.

PERSONAL BUDGETS and DIRECT PAYMENTS

A 'personal budget' (PB) identifies the cost of providing an individual's community care services, allowing the individual to determine (within limits) how the budget will be spent. The PB can either be managed by the local authority in line with the service user's wishes or can be handed over in the form of a 'direct payment' for the service user to manage.

Personal budgets need to be available within a system that:

- Offers personalised, responsive care without direct payments
- Makes the managing of PBs to be as easy as possible with support for those who find it hard.
- Enables PBs to be pooled so that a group or groups of people can collectively benefit.

While the SHA does not envisage personal budgets or direct payments being the main model of social care delivery, they do provide some service users with a welcomed the flexibility of direct control and decision-making not mediated via a third party. However, they carry significant risks which must be mitigated. These include:

- The same fixed personal budget will buy many more hours of shared care in a communal setting than hours of 1-to-1 support. Many service users enjoy shared provision.
- Large numbers of direct payments mean less funding for core communal services such as day centres or activity-based services where people may enjoy collective activities with friends. This can mean that communal services valued by other users are no longer viable.
- Individual funding results in a fragmented system and can increase isolation.
- Direct payments often involve complex paperwork and bureaucracy. Anyone employing staff directly will take on employer responsibilities as well as difficulty covering staff holidays, sickness etc.
- Less protection for staff who are employed directly by service users.
- Personal budgets may be used to fund unregulated services that may be poor quality or even unsafe.
- It may be politically easier to cut funding for individual budgets than funding for popular communal services.

THE WIDER PARAMETERS OF SOCIAL CARE

We need joined up thinking with other government policy areas which are beyond the general scope of the SHA though they are very important from the public health point of view in promoting the well-being and quality of life of all citizens including those with social care and support needs. This will include:

- **Housing policy:** build all new housing to lifetime standards with doorways, hallways, rooms wide enough for wheelchair access and level floors. Housing developments to always include some housing that is fully wheelchair-user accessible etc
- **Public transport:** fully accessible / access to assistance; all local planning to meet required standards of accessibility etc
- **Leisure services:** include disabled access
- **Community development:** communities incentivised to include and support elderly, vulnerable and disabled people in community activities and local decision making and planning.

APPENDICES, REFERENCES AND OTHER ADDITIONS.

APPENDIX ONE

DEFINITIONS

[The Law Commission's](#) definition of "social care" is:

"The care and support" (note the change of language) " provided by local social services authorities pursuant to their responsibilities towards adults who need extra support... Adult social care services include the provision by local authorities and others of traditional services such as care homes, day centres, equipment and adaptations, meals and home care. It can also extend to a range of so-called non-traditional services - such as gym membership, art therapy, life coaching, personal assistants, emotional support, and classes or courses. ... Finally, adult social care also includes the mechanisms for delivering services, such as assessment, personal budgets and direct payments."

The Royal Commission identified three quite distinct types of care that frail older people need. They are:

1) Living costs/board and lodge

At present, funding for care in a hospital or care home, includes funding for board and lodge. This discriminates against those who receive care at home (who pay for their own board and lodge) in favour of those who receive care in a care home or in hospital.

2) Support services (e.g. housework, meals on wheels etc)

the Royal Commission described it as among *"the wide range of services designed to support people to maintain their independence, enable them to play a fuller part in society, protect them in vulnerable situations and manage complex relationships"*

3) Direct care/personal care.

Personal care requires DBS checks. This means all direct care related to:

- a. Personal toilet (washing, bathing, skin care, personal presentation, dressing, and undressing).
- b. Eating and drinking (as opposed to obtaining and preparing food and drink).
- c. Managing urinary and bowel functions (including maintaining continence and managing incontinence).
- d. Managing problems associated with immobility.
- e. Management of prescribed treatment (e.g. administering and monitoring medication); behaviour management and ensuring personal safety (for example those with cognitive impairment, minimising stress and risk).
- f. Personal care also includes the associated teaching, enabling, psychological support from a knowledgeable and skilled professional, and assistance with cognitive functions) that are needed either to enable a person to do these things for himself /herself or to enable a relative to do them for him/her.

SHA comment on Living costs/board and lodge: both those at home and those in residential care can be discriminated against financially in different circumstances.

APPENDIX TWO

LABOUR TO ESTABLISH A TASKFORCE INVOLVING USERS AND CARERS/TRADE UNIONS/RELEVANT ORGANISATIONS TO DELIVER AN INDEPENDENT ADVOCATE SYSTEM AND NATIONAL INDEPENDENT LIVING SUPPORT SERVICE.

SHA supports a taskforce to explore these issues. SHA does not endorse any particular solution. The SHA regards the concept of disabled people to include people of all ages and conditions.

The following are suggestions from the ROFA document, [“Independent Living for the Future”](#) referred to above and in ref 1. It aims to move towards a national independent living service capable of upholding and implementing Disabled people’s Article 19 rights.

We recommend a system underpinned by the social models of disability and distress that can be accessed by all disabled people regardless of impairment or perceived impairment. Our vision for a national independent living support system would also eliminate the post code lottery that exists within current local authority and CCG administered provision.

The social care element of Disabled people’s right to independent living would be administered through a new national independent living service managed by central government, but delivered locally in co-production with Disabled people. It would be provided on the basis of need, not profit, and would not be means tested. It would be independent of, but sit alongside, the NHS and will be funded from direct taxation.

The national independent living service would be responsible for supporting disabled people through the self-assessment/assessment process, reviews and administering payments to individual Disabled people. Individuals would not be obliged to manage their support payments themselves if they choose not to.

ROFA suggest the following steps to achieving this aim:

1. Office for Disability Issues to be placed within the Treasury, Cabinet Office or the Government Equalities Office to give it more reach across different Government departments.
2. Formation of an independent living taskforce with a meaningful influence, led by Disabled people from all demographic backgrounds who need/use independent living support.
3. Funding to make a case for investment in independent living support, including evidencing social care as a social and economic generator and what wider benefits could be saved from savings to NHS budgets.
4. Model the amount of funding needed to ensure good quality independent living support meeting need now and in the future to uphold all Disabled people’s rights under Article 1913.
5. Funding of user-led research into alternative service options and culturally appropriate resources for Disabled people.
6. A communications strategy for raising awareness about what we mean by independent living, Disabled people’s human rights and the role of Personal Assistants.
7. Dealing effectively with stigma against Disabled people whether at political, commissioning, or service levels, or within society as a whole.

-
8. The funding of adequate training for government personnel, commissioners and service providers about the meaning of independent living and its value, led by Disabled people.
 9. A strategy for investment in local user-led, public sector and co-operative provision to replace private sector social care agencies/homes.
 10. A strategy for closure of institutionalised, segregated settings including long stay hospitals and Assessment and Treatment Units replaced with independent living service in the community.
 11. A housing strategy based on universal design, accessibility and lifetime homes principles embedded in and part of the commitment to the building of social/public housing
 12. Fund work to draw up a case for investment in Access to Work, evidencing the level of return on investment to the treasury for every pound spent.
 13. Roll Access to Work into the national independent living service.

APPENDIX THREE

SERVICE CHANGES BEING PROPOSED BY THE TRADE UNION MOVEMENT INCLUDING THE GMB AND UNISON.

- Training, occupational registration, concern for safeguarding, terms and conditions of work and funding are intricately connected and improvements must be made on all fronts to recognise and reward the skills and professionalism of care workers.
- Better learning outcomes for care workers and professionalisation of the sector cannot materialise in the absence of security of income, security of hours of work and protection of workers' wellbeing and health.
- The extensive skills involved in care work and support make it wholly inappropriate for care workers' wages to be pegged at or around the applicable statutory minimum wage rates. Recognition of the professionalism of care workers means wages must be put on a professional footing.
- Action is needed to reach agreements about minimum standards across the sector so that all workers are included. There is a need for sector-wide agreements on training and learning to be reached by negotiation between employers' and workers' representative organisations. Agreements on core terms and conditions of work should sit around this.
- The fragmentation of the care industry (with approximately 25,000 registered providers in over 50,000 locations) presents a difficulty for enforcing higher training and qualification standards within regulatory structures that enable considerable employer discretion.
- The basic skills (literacy, numeracy and I.T.) needs of the care workforce must be addressed with sensitivity and urgency in order to support training requirements set out in regulations and to overcome a big potential barrier to successful registration.
- Care workers need to be recognised for their skills in engaging and negotiating with unpaid carers as well as with professionals in other health and support roles.

-
- More information about the self-funded care and support market is needed.
 - An absence of registration (and, to a large extent regulation) is characteristic of the PA sector and there is a need for more research and greater understanding of the interrelationships between the PA sector and other sectors of the care market.
 - Body work is an under-recognised skill component of care work practices. To value care work properly there must be stronger regard and recognition of the skills and knowledge of body work. It should also be explicitly included as a requirement in regulation about training.
 - The skills of care workers in respect of end-of-life care are often overlooked in accounts of their professionalism.
 - Training in the promotion of personalisation in policy and care workers' knowledge, understanding and ability to put these concepts into practice.
 - All care workers need training in health and medically related skills and knowledge about complex conditions like dementia and diabetes for hands-on care work.
 - There is a substantial need for care workers to develop skills in conflict management, motivating others, team-working and organisation.
 - There is very little information and research about on-the-job training, such as shadowing or observation shifts. This form of training is routinely used in the sector but is rarely mentioned in academic or policy literature.
 - Regulation, or regulatory guidance, should ensure that time required to be set aside for training is paid time.
 - Care workers who are shadowed should be recognised as trainers in key practices and as peer-to-peer communicators of essential knowledge.
 - There is a marked difference in the regulation of training and workforce standards in England, and elsewhere in the UK. It seems timely to review the decision to reject registration in England on cost grounds.
 - The initiative taken by devolved nations to introduce and advance registration would be supported and assisted if England were also to develop a registration scheme for care workers because the vast majority of the U.K. care workforce are based in England.
 - There is evidence that regulatory initiatives for the occupational registration of care workers and workforce matters are aligned with recognition of the importance of job quality to care quality (for example on zero hours contracts in Wales, on staff wellbeing considerations in Scotland, and the density of temporary workers in Northern Ireland). However, devolved nations are not able to make legislation or regulate directly on matters of employment.
 - Professionalisation via worker registration and prescribed training standards is most advanced in N. Ireland. Sanctions on providers for engaging workers who are not fit to work in care and for breaching staffing standards appear strongest in Northern Ireland.

➤ Sanctions on employers for failing to appropriately train, supervise or appraise care workers are inconsistent across the UK and need to be made consistent. It is hard to understand why it is a prosecutable offence in Scotland for providers to engage workers who are not fit to practice, but not so in England without proving avoidable harm or significant risk.

➤ A significant marker of professional status in Wales is that an unregistered person commits a criminal offence if they take or use the title ‘social care worker’.

APPENDIX FOUR

These are interim measures that can be taken now - recommendations of the Centre for Health and the Public Interest report [“The failure of privatised adult social care in England: what is to be done?”](#)

1. Where a public body has a legal contract with a private provider, the contents of that contract should be fully transparent.
 2. The ownership details of companies providing public services under contract to the public sector should be available for public scrutiny.
 3. Private companies in receipt of public services contracts should be domiciled in the UK and subject to UK taxation law.
 4. Consideration should be given to giving local electorates powers to call to account any provider judged to be providing an inadequate service.
 5. All providers should be required to comply with minimum standards of workforce terms and conditions and to accept collective bargaining rights.
 6. There is scope to impose a contract on private companies that places an upper limit on what constitutes a reasonable return on investment. This scope should be exploited.
 7. Organisations with a social purpose should be defined as the preferred providers of care and support services.
 8. Steps should be taken to rebuild providing capacity in the statutory and not-for-profit sectors.
- (p21)

APPENDIX FIVE

MORE DETAIL ON COSTINGS FOR FULLY FUNDED SOCIAL CARE AND SUPPORT
With thanks to [Reclaim Social Care](#)

Over the life of one Government (5 years) there is no reason why the following objectives could not be achieved:

- Commit to end means-testing for Social Care. This might mean having to fund about **£10 billion** (current cost of privately purchased care) and a further **£1 billion** (income from charging).
- Commit to increase the overall level of support provided. Returning to the level of Social Care available in 2009 (a 44% increase) will cost approximately **£6 billion**.
- Commit to increase the salary levels of support staff, say by 25%, which implies a cost of about **£5 billion**.
- Commit to an increase in progressive taxation to pay for the introduction of a new and improved universal Social Care service. Note that, while this means that the better-off will be paying more in tax they will actually reducing risks and costs for themselves - should they or those they love acquire a disability - at any stage of life, including old age.

-
- Commit to reduce pay inequalities, capping top salaries and aiming for a salary ratio of 1:3 between direct staff and top management (this will also radically improve efficiency by making more direct support available).
 - In total this implies a total cost increase, after 5 years, of £22 billion, bringing the total cost of Adult Social Care in England to about **£40 billion** or 2% of GDP. This is of course a very rough estimate, and it does not count in savings from cutting out wasteful administration or savings for other public services.

This figure is completely affordable and is funded by providing a clear entitlement to a universal service to people who are currently having to either pay for that service or who should plan to pay for it in the future.

We need to see Social Care as investment in community life - an investment built on a partnership between people who are disabled, and those with long term health conditions and co-morbidities etc., and families, communities and professional staff.

APPENDIX SIX

UN PROVISIONS

[The UN Rights of Persons with Disabilities](#) sets important benchmark. These rights are not appropriate for all, on safety and compassionate grounds, but should be a right for those for whom it is achievable.

Article 19 – Living independently and being included in the community

We expect the government to recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Article 25 – Health

We expect the government to recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. The government shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation.

In particular, the government shall:

- a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;
- b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;

-
- c) Provide these health services as close as possible to people's own communities, including in rural areas;
 - d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;
 - e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
 - f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

Article 24 – Education

1. We expect the government to recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, the government shall ensure an inclusive education system at all levels and lifelong learning directed to:

- a. The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;
- b. The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;
- c. Enabling persons with disabilities to participate effectively in a free society.

2. In realizing this right, the government shall ensure that:

- a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;
- b) Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;
- c) Reasonable accommodation of the individual's requirements is provided;
- d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;
- e) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.

3. The government shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community. To this end, the government shall take appropriate measures, including:

- a) Facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring;
- b) Facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community;
- c) Ensuring that the education of persons, and in particular children, who are blind, deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development.

4. In order to help ensure the realization of this right, the government shall take appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign

language and/or Braille, and to train professionals and staff who work at all levels of education. Such training shall incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.

5. The government shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others. To this end, the government shall ensure that reasonable accommodation is provided to persons with disabilities.

APPENDIX SEVEN

LABOUR'S MANIFESTO COMMITMENTS 2019

The following is a summary of the main proposals in the Labour Party's 2019 election manifesto.

- interdisciplinary, patient-focused services across primary care, mental health and social care.
 1. A comprehensive children's health strategy
 2. A comprehensive National Care Service for England, working in partnership with the NHS, ensuring care is delivered for people, not for profit.
 3. Community-based, person-centred support, underpinned by the principles of ethical care and independent living.
 4. Free personal care, beginning with investments to ensure that older people have their personal care needs met, with the ambition to extend this provision to all working-age adults.
 5. We will develop eligibility criteria that ensures our service works for everyone, including people with complex conditions like dementia.
 6. We will ensure no one ever again needs to face catastrophic care costs of more than £100,000 for the care they need in old age, which we will underscore with a lifetime cap on personal contributions to care costs.
 7. Additional care packages to support both older people and working-age adults living independently
 8. More than double the number of people receiving publicly funded care packages, improve the standard of care provided to them and remove the distinction between health and care needs.
 9. Support autistic people and people with learning disabilities to move out from inappropriate inpatient hospital settings and provide support in their own homes