# **Stabilise, energise, realise:** a long term plan for social care

FUTURE HEALTH

Alzheimer's Society
United Against Dementia

# Contents

# **Foreword –** Fiona Carragher

Everyone deserves to be able to live a life with meaning, purpose and connection. Where people need support in order to do this – as many people with dementia do, as the condition progresses – care should be there.

We are all familiar with the safety net of the NHS – we know we can access good quality care when we need it, free at the point of use. But many people aren't prepared for the reality of social care – a struggle to access care, high and often catastrophic costs, and care that is often only basic and doesn't meet people's needs. For people with dementia, this is a challenge they face – and one that is deeply unfair. The impact is not only seen for people with dementia themselves but also the unpaid family carers, many of whom see an impact on their own health and wellbeing, as well as on their ability to remain in work. Alzheimer's Society has been relentlessly campaigning on these issues over many years, amplifying the voices of people affected by dementia and working with our campaigners to demand change.

We recognise the scale of the challenge. But what we don't accept are excuses to consign social care to the 'too difficult' box, to leave as a problem for another politician on another day. The failure to act to address the issues in social care is unfair for people with dementia and their families who have to live with the consequences of the inaction of government every day.

In this report, we seek to set out what needs to happen and how to deliver a social care system to be proud of as a nation. We want to work with the Government to address this challenge and develop the solutions.

Integration of health and social care has been a goal of government for some time now. But to truly achieve this, the NHS and social care must be seen to be on an equal footing. The NHS has a Long Term Plan and a workforce plan, this report sets out the initial building blocks for both for social care. This fundamental commitment to social care needs to be paired with significant investment in research through the Dementia Moonshot, and a genuinely ambitious and properly resourced National Dementia Strategy to address the specific challenges faced by people affected by dementia.

This report builds on our position on the quality of care set out in our paper, *A Future for Personalised Care*. As we continue to move towards reform, we will need all voices to amplify this goal of personalised care based on what matters to people, as set out in the vision of Social Care Future and supported by many leaders across the sector.

While there are many statistics on the impact of the lack of proper support, behind each of these numbers are individual people with dementia and their families, living with the reality of this day by day. In this report you will hear from just some of the people that Alzheimer's Society and Future Health have engaged with in the development of this work. Each tells just one story of an individual and their family and how their life has been impacted, not by their experience of dementia, but by their experience of social care. It doesn't have to be this way. While dementia isn't curable yet, we can *#CureTheCareSystem*.

**Fiona Carragher**
Director of Research and Influencing, Alzheimer's Society

# **Foreword –** John, Greater Manchester, living with dementia

A dementia diagnosis was never going to be an easy thing to hear. But I wasn't expecting to feel so abandoned. My post-diagnosis support was almost non-existent. I couldn't understand why it was so focused on benefits. As someone who had worked in the benefits system for 20 years, it just didn't make sense. It was so impersonal to me and my needs. I needed information on care options and support, but this was sparse and difficult to find.

I had made a will to make sure any assets I have were passed on to those close to me. But I know I will at some point need to go into a care home, and that the will I have made is defunct as my assets will be drained away. How is this fair?

Eventually we did find some help and signed up to a course of post-diagnosis support. However, my wife and I contacted the organisers shortly before the first session to confirm our attendance and found we had not been booked on properly. She had taken time off work to support me. There were no other courses available. She won't get the time back now. We have managed to find some help through working with Alzheimer's Society, but we need a better system. People need to know what help is available to them. People are not being given the support they need to plan for their futures. The system is too complicated and not focused on the needs of the people it supports and those who care for them. Services don't reflect what users need or want. The CQC should make sure people with dementia and their carers are consulted on the quality of services.

People in social care have been forgotten and ignored for too long. Now is the time for Government to make some real changes to social care. We need a fairer system that gets people the help and support they want and need.


**“We have managed to find some help through working with Alzheimer’s Society, but we need a better system. People need to know what help is available to them.’**

John

# Report summary and recommendations

## This report from Future Health and Alzheimer's Society sets out ways for Government to deliver a better future for social care through a new social care long-term plan.

In 2019, the Government recognised the need for the NHS to transform itself over the next decade to meet rising and changing demand. Over £30bn of extra funding was committed over the first half of the plan to deliver this transformation[1].

Following the pandemic and many years of inaction and false starts, now is the time for similar action in social care. This ten-year plan for social care sets out a number of areas where action is needed with the aim of ensuring that social care looks radically different in the 2030s compared to how it does today.

More funding is undoubtedly required to deliver improvements in social care. This includes continuing to support the system through the pandemic, as well as addressing catastrophic care costs people with conditions such as dementia can face following a diagnosis. Investment will also be required to improve care quality and expand the number of people who are eligible for publicly funded care.

The Spending Review is going to be challenging for Government due to the pandemic. But Governments are elected to make tough choices, and over two years have passed since Boris Johnson's pledge to bring forward a plan to 'fix' social care. This plan argues that tax rises from general taxation will raise sufficient revenue to begin to make some of the most important changes and tackle unfairness in the system. This would include introducing a cap on care costs and making care more personalised and tailored to the individual.

Alongside the provision of additional funding, there needs to be serious and sustained reform. Collectively, we must find new ways of looking at, and talking about, our social care system. Reliance needs to be replaced with empowerment. Direction with choice. Institutions with control. By engaging those who use and need access to care, their carers, and the wider public, we can transform our social care system so that it helps people live in the places they call home, doing the things that they love to do.

Far greater effort needs to go into this public engagement. Government should launch a new national conversation on social care. While this has been another part of reform continually put off, it is a necessity to facilitate proper public discussion and debate on this subject. Without it, the social care narrative is reduced to one of simply protecting or selling family homes, rather than on improving access to higher-quality care and support. This report has sought to begin this process. What kind of care do we want for ourselves and for our loved ones? Too often people who rely on care are treated as passive recipients who have things done to them. What do they need to live their best lives and contribute to society in the best ways they can?

The over-riding approach in this long-term plan for a better social care system is to deliver more personalised care. This is not the same as free personal care, which is a set of defined physical and impersonal tasks. Rather it is about providing care that starts with a simple question: 'what matters to you?' The plan also seeks to deliver a system that tailors care around the needs and wants of the individual involved.

The core principles for this should be social care that:

Offers choice and control, responds to changing needs, actively seeks feedback, and encourages and supports people to maintain their independence

Supports the individual with choosing and setting their own goals

Recognises the importance of relationships to health and wellbeing

Improves peoples' experience of living well – including measuring psychological factors such as optimism, self-esteem, loneliness and depression[2]

The opportunities for delivering this have never been greater. New technologies, new housing developments and greater awareness of the environment all present opportunities to build a dynamic and improved social care system.

We are in an era of significant technological expansion and innovation. The 2020s will only see this accelerate. This long-term plan looks at how social care can benefit from this change. We need to build more homes, so how can we make more of them 'care ready'? How can we build new alliances across health and social care to co-operate and tackle problems collaboratively? How can we utilise the opportunities of the green agenda to improve care quality and reduce our care carbon emissions? How can we tackle digital exclusion so more people can benefit from technological advancement? How can we reward UK innovators and entrepreneurs who come forward with ideas to improve the quality and choice of care available? As a generation of people with greater digital literacy grow older and develop dementia, how can 'care' keep pace with their expectations?

The benefits of getting this right for society and communities across the country are wide-ranging. Support for family carers can help their return to work Improvements in health and wellbeing, mental health and community connectivity can support local economies and businesses, tangibly demonstrating examples of 'levelling up.'

To support long-term improvement, the Government should build a 'social care sector deal', similar to that undertaken in other parts of its industrial strategy; such as life sciences. This would help encourage new investment in the sector and allow for the exploration of financing options for improvements in social care. This long term plan also argues for a review of the social care provider market and the investigation of ways to expand the variety and type of providers available to those accessing care and support. Any such deal should incorporate the views of those accessing care and support to shape the future market and options.

Any long-term social care plan needs a social care people plan at its heart that delivers for those accessing care and support. This long-term plan proposes a four-part strategy of retain-attract-train-progress. Government must also ensure providers pay care staff rates that reflect fair, nationally-set rules; build campaigns and programmes to attract more people into the sector; support new types of training, development and career progression; and launch a consultation on a national register of care workers to assess the impacts of any such move. Ensuring the future workforce reflects the needs of users will be critical, and efforts to expand roles such as Link workers – who can help support the objective of keeping people living in the place they call home – should also be included in any workforce plan.

Through raising funds; tackling unfairness; listening to those accessing support and their carers; unlocking the opportunities from new technologies; leading a new public conversation; reforming and overseeing the provision of care; improving training; and expanding new roles that support care closer to home, the Government and its partners can transform social care over the next 10 years.

Doing so will meet the goal of more people being able to say they are cared for in the place they call home with the people and things that they love, in communities where people look out for one another, doing the things that matter to them.

# Recommendations

## Funding

1. The social care system should continue to be financially supported by Government, particularly with the challenge of managing the pandemic through the 2021/22 autumn/winter period approaching. The Adult Social Care Infection Control Fund should be extended to March 2022.

2. The Government should increase funding for social care at the Spending Review to stabilise the system and begin re-designing it to transform lives. This funding should come from general taxation. Any tax rise should not see funds prioritised for the NHS ahead of social care.

3. As part of the funding package, the Government should swiftly address the issue of catastrophic care costs by bringing forward a cap on care costs which recognises the true costs of care and is set at a level which protects people from catastrophic costs and raises the floor at which people pay towards the cap.

4. By the end of this Parliament (expected to be 2024), Government should move to introduce 'free personalised care' for those eligible in England, through which people are supported around their needs and the central question of 'what matters to you?'. The cap and floor should be adjusted to reflect the introduction of this care model.

## Public engagement and information

5. The Government should launch a national conversation to engage the public on what people want and need from social care, future funding and reform options.

6. The final NHSX data strategy should set out how better data and information will be made available to support those accessing social care to have more choice and control, and to secure care that is better personalised to their needs. This should also align with the recently published CQC strategy.

7. The Department of Health and Social Care should refresh the Adult Social Care Outcomes Framework to include more performance measures on personalised care; such as if care is delivered in the place requested by the individual receiving care and if choices of care are offered.

**8.** The Department of Health and Social Care and NHS should establish a Dementia Observatory to track data on outcomes for people with dementia. A National Dementia Experience Survey similar to the National Cancer Patient Experience Survey should be established and used to assess the quality of dementia care.

**9.** The Department of Health and Social Care should work with the Department of Culture, Media and Sport and the Cabinet Office on a plan to eliminate digital exclusion and support the use and uptake of new technologies in social care, including residential and domiciliary care.

## Workforce

**10.** The Government should develop a ten year social care People Plan underpinned by efforts to retain-attract-train and progress the social care workforce.

**11.** Government should launch a new national campaign that encourages people to enter the social care workforce. Such a campaign must learn lessons from previous campaign efforts, and crucially, reflect the views of those accessing services.

**12.** The Department of Health and Social Care should set up a national social care board to ensure social care sector pay is fair and properly monitored. The Board should consider how to more closely align NHS and social care sector pay-scales.

**13.** Government should continue to invest in the social care workforce and its progression and development. The Workforce Development Fund between the DHSC and Skills for Care should be significantly expanded and training efforts focused on improving staff skills on delivering personalised care.

**14.** The Government should launch a consultation and engagement exercise with those using and working in social care regarding the professional registration of staff and the impact such a register would have.

**15.** Government and the NHS should make efforts to expand relevant areas of the workforce to ensure more people can be cared for in places they call home.

## Quality

**16.** The Government should use the Care Act 2014 principles to underpin efforts on improving care quality to ensure that care is more personalised and focuses on what matters to people. Central to such reform should be the setting of a vision for improved care quality in collaboration with social care users and carers, and increasing the use of personal budgets in commissioning.

**17.** NHSX and NICE should collaborate to develop a process for kite-marking and accrediting new technologies in social care to support the use of high-quality solutions and interventions.

**18.** The Government's plans for 300,000 new homes a year should ensure that homes built are 'care ready' and that the guidance on lifetime homes is strengthened.

**19.** The Government should follow up on the National Audit Office review of the social care market and commission its own review of the social care provider market with an explicit objective of diversifying and expanding the market to support the policy objective of keeping more people living independently in their own homes.

## Integration

**20.** MPs and Peers should use the Committee stage of the Health and Care Bill to ensure ICS boards include representation from social care, including commissioners, providers and voluntary groups.

**21.** As part of the development of ICSs, NHS England and the CQC should ensure that ICSs are held to account for their engagement with social care commissioners, providers and voluntary groups through an appropriate set of metrics and feedback processes.

**22.** As part of their establishment, ICSs should work with local authorities in undertaking and developing ICS-wide Joint Strategic Needs Assessments to capture the health and care impacts of Covid 19 and support the effective allocation of interventions and resources as new healthcare strategies are set.

**23.** NHSX should ensure that people have access to a joined-up health and care record by 2025 as advocated by ADASS and TSA.

**24.** Government, NHS England and the CQC need to balance their oversight of new ICSs with the importance of 'place-based' approaches to care and support. It is critical that place-based approaches are allowed to thrive and innovate in the new system and are not over-powered by regional structures.

## Carers

**25.** The upcoming Spending Review should recognise the efforts of carers during the pandemic and see an uplift in funding to support carer breaks.

**26.** The final NHSX data strategy should set out measures for tackling gaps in the data available to local authorities on carer needs in their area. This should include (a) the number of carers assessments offered and number taken up, with the reason for their caring responsibility (e.g. the condition(s) of the person they care for) also recorded; (b) the number of short breaks for carers provided recorded, including the type of break.

**27.** Local authorities should consider ways to identify carers earlier through Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies. Carers should be provided with early assessments of their needs upon identification, and ongoing assessments if they are caring for people with progressive conditions such as dementia.

## New Technology and Investment

**28.** The Department of Health and Social Care should include a £450m proposal to replace current care and housing infrastructure proposed by ADASS within its Spending Review Treasury bid.

**29.** The Government should review the challenges of capital investment and incentives in social care and consider how existing schemes such as LIFT in the NHS could play a greater role in supporting capital investment in social care facilities and re-designing care.

**30.** The Government should explore working with organisations across the social care sector to build a 'Social Care Sector Deal'. The deal would see public, private, voluntary and philanthropic organisations come together to develop ideas and a range of new investment opportunities for transforming social care and unlocking the potential of new technologies.

# **Social care in the 2030s:** The vision and opportunity

We all want to live in the place we call home with the people and things that we love, in communities where we look out for one another, doing the things that matter to us.[3]

As articulated by Social Care Future, the next decade presents new opportunities to transform social care and deliver on the vision for what a better social care system should be for those who matter most – those who draw on care and support.

The pandemic has told us what we already knew about social care: that our social care system is not delivering what is needed for those who need it.

The challenges are deep and wide ranging – staff shortages, challenges and variations in access to care, unfair means tests and a lack of personalised support.

Polling by Survation on behalf of Social Care Future in 2020 found the three most dominant words people associated with social care were words focused on dependency: compassion, vulnerability and safety. But there were reasons in the survey to be optimistic of a future supporting greater independence. "61% of people also agreed with the more positively framed statement that social care is 'about having the support they need to live how, where and with whom they choose' and 60% agreed that 'I support greater government investment in social care'[4]."

This optimism needs to be harnessed to finally face up to the issue of social care reform and transform how we look at it. To 'build back better' will require a different narrative and approach from what has come before. The reforms to the health system set out in the Health and Care Bill, including for more integration of health and social care, will not work without a proper plan for social care.

According to the Office of National Statistics, it is projected that one in four people in the UK will be aged 65 years and over by 2050 – an increase from approximately one in five in 2018.[5] As with rising concern about climate change and ambitions to move to 'net zero', the growing importance of social care can play a major and positive role in the economic, social and cultural renewal of our country and its communities.

In her book *Extra Time*, Camilla Cavendish articulates what this opportunity looks like: "we need to be much more ambitious for ourselves, and for our health systems, which must change from factories which were built to heal the sick, and send them on their way, into networks which help people stay independent and healthy as long as possible[6]." Supporting such greater independence will see the creation of new innovations, ways of working, collaboration, and greater productivity and societal participation across the country. For a Government that is committed to 'levelling up', social care that delivers on the needs and wants of individuals can be a major asset for local community regeneration.

A ten-year plan for social care has widespread support and would mirror the long-term planning afforded to the NHS through its own Long Term Plan. This ten-year plan for social care in England, drawn together by Future Health and Alzheimer's Society, has been built through a series of roundtables and interviews with over 40 organisations and individuals across the breadth of social care. Critically, this has included and prioritised people with lived experience and their carers through a set of interviews and discussions captured as case studies in the report.

Perhaps inevitably in writing an overarching long term policy plan aimed primarily at Government and policymakers, the document can at times feel remote from the personalised agenda it seeks to champion. However, the discussions with individuals who draw on care and support that have informed the recommendations and that have been included as case study examples throughout this report seek to demonstrate the actions and benefits that can be realised if we rise to the challenge and deliver an ambitious long term policy plan.

The document sets out a three-part programme of change that any Government long term social care plan should deliver. This includes the need to stabilise the system following the devastating impact of the coronavirus pandemic, energising the system through new levers and assets such as technology, housing and personalisation, towards a final phase of full transformation by the end of the decade that will see a wide range of benefits realised.

To deliver on what those who draw on social care need and want will require new policy action in three important areas: funding, workforce and quality. These pillars if properly tackled can underpin a better social care system and deliver on the vision that sees more people living in a place they call home, in communities where people look out for each other, doing the things that matter to us.

# **Transforming social care:** The political opportunity

For Government, social care has never been enough of a priority for change. When faced with a choice of investing in the NHS and social care, there has only been one winner.

Politically this is no surprise. When voters are asked to rank issues of importance, the NHS inevitably comes out near the top whilst social care, poorly defined and understood, struggles to cut through. When social care policy proposals are put forward, they either emerge with limited consultation and public engagement, or are subject to such lengthy discussion and consultation that they never reach implementation. The last ten years have proven beyond doubt that putting social care proposals forward close to or during election periods is a grave mistake that sets back the agenda for many years.

As we now reach the middle of this Parliament, with the impact of the pandemic on those in social care clear and with a Spending Review looming, politicians have an opportunity to step forward with new proposals and a new mandate to start conversations with the public on what needs to happen next.

The failures of the last 30 years make it clear that framing this problem through one of mere asset protection and loss will not succeed. Instead, the new political conversation on care needs to be about how to build a better long-term system for those who draw on it and work within it. At this present moment, we have unique opportunities to deliver a dynamic period of change in social care.

**For politicians, change in social care can deliver on a number of positive and forward-looking agendas for change:**

## Global Britain

Supporting ambitions for Britain to be a global leader in areas of scientific research and discovery, such as dementia.

## Levelling up

More people across the regions of the country can access the care and support they need and are supported by their communities in living independent and full lives tackling regional health and wellbeing inequalities.

## Economic growth

Health and social care is one of the most dominant employers across the country and part of the 'foundational economy'. The foundational economy are services and products that are a core part of communities and bring people together. For example carers with greater support could be economically active. This is also not just public sector jobs, but a growing third and private sector working in partnership and through supply chains to deliver the support people need and want. The Welsh Government is funding work aimed at supporting the foundational economy which policymakers in England should consider in their social care plans.[7]

## Innovation

There is a growing level of investment in social care innovation that can support people to live independently and deliver more preventative and proactive care. There is a growing SME and not-for-profit community of companies based in the UK bringing ground-breaking innovations to market.

## The homes of the future

Building more homes is rightly a priority, and in thinking about new house-building there are major opportunities to look at dynamic new housing for older people and those with care needs. This includes investing and upgrading in existing care facilities such as care homes.

## The environment

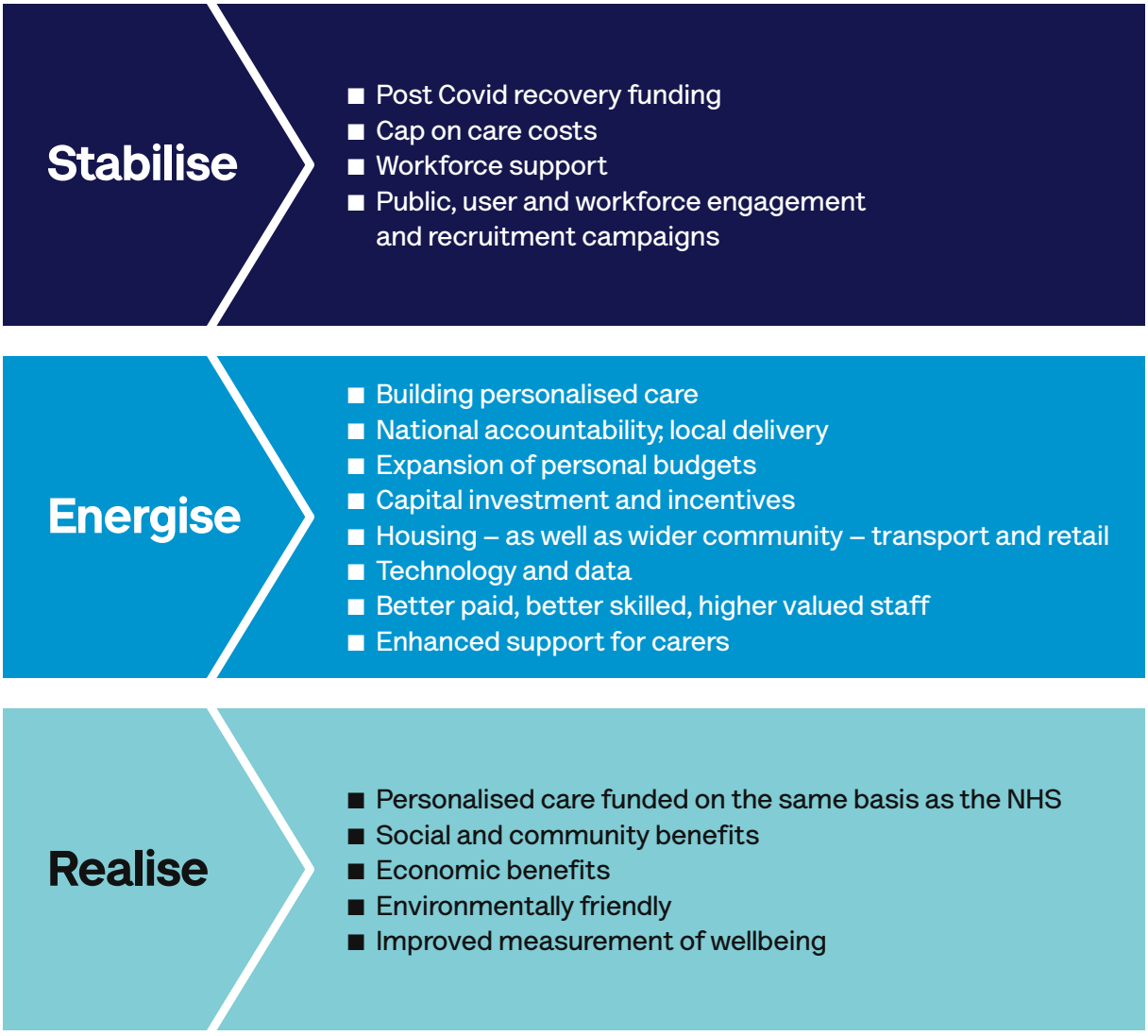
As a major employer and deliverer of public services, there are substantial opportunities for social care to support a greener Britain. Access to green spaces and natural habitats has been shown to improve people's experience of care.[8]

# **Delivering the vision:** The ten-year plan for social care

Enacting the vision for better social care will need to happen in phases. The problems of social care will not be addressed in one set of changes, but require concerted, co-ordinated and ongoing effort to deliver.

The ten-year plan for social care will cover multiple Spending Reviews, cross general elections and potential changes of Government. In order for it to endure, it will be important that it is developed closely with the social care sector and those who draw on care and support, in a similar way to the NHS Long Term Plan.

The proposed phases are set out in more detail below.




The impact of Covid on the social care sector means that the time is now right to start this journey. The 2021 Spending Review should be the start of the changes that are long overdue.

## Stabilise

The immediate priority is to stabilise social care and put it on a more secure footing for the future. This should include ensuring that the sector continues to receive adequate funding for any ongoing actions for handling the pandemic.

New funding plans must also be brought forward. As set out by Andrew Dilnot, this should include a cap on care costs, ensuring that no one faces catastrophic care costs running into the hundreds of thousands of pounds. This can be done swiftly by using existing legislation.

The Government should also utilise the heightened interest in social care to launch a national conversation on social care. This would be a public conversation to get a wide range of views on what the future social care system should look like and what it should deliver for those who need access to care. The national conversation will underpin the reform journey and ensure momentum is built and maintained. This leadership and public engagement will also be helpful in supporting the important task of recruiting the workforce of the future[9].

## Energise

The Dilnot cap transfers some risk from the individual to the collective, but does not inject any new funding into an under-funded system. Therefore alongside it, additional funding is needed to ensure people get the care and support they deserve. This should be 'free personalised care' that is care tailored to the needs and wants of the individual. This would go further than the free personal care provided in Scotland and would seek to reflect people's individual goals and support their connections to their local communities[10]. It would take care beyond a set of physical tasks and enable far greater flexibility in the approaches used based on the needs and wants of the user, including far more opportunities to access care within the community. The Government should set out a timeline for introducing free personalised care in this Parliament, including increasing council budgets to pay for more complex packages of care that take into account someone's holistic needs. We also need to see increased access to care, so that people with moderate needs can draw on support and not be forced to wait until crisis point. The Health Foundation has calculated that to deliver this would cost an additional £14.4bn by 2030[11].

As progress is made with elements of personalised care being delivered free at the point of use, the cap and floor should adjust to ensure that people are not inadvertently expected to pay more to meet the cap. General taxation should be used to cover the costs of the cap and of 'free personalised care[12]'. Our long-term goal should be care funded on the same basis as the NHS and schools, where the risk of paying for care is shared across society.

This second phase of reform will look to energise change and deliver on the vision for personalised social care. It will see local communities taking a prominent role through asset-based approaches to social care; building off pioneering work already underway in places such as Manchester and Wigan[13]. Integrated Care Systems will develop dementia plans based on these localised approaches.

Incentives will be developed to encourage capital investment in the sector and greater co-ordination between social care and housing will help support more people to live independently.

Work on the ageing society through the industrial strategy will deliver innovation[14]. New technologies will play a major role in this alongside improved data and intelligence that can support greater integration between the NHS and social care and enable a shift in care to more proactive and preventative models. Smart homes and design will support many more people to live in their own homes for longer.

As pay and the sector's value both increase, more people will be attracted to work in the sector. New career paths and progression will reduce levels of staff turnover.

Carers will have access to more support including improved funding for breaks and have greater recognition across the health and care system for the role they play.

## Realise

Towards the second half of the ten years, we will have reached the transform phase, where the changes from re-designing the system start to be locked in. At this point, more people are able to live in the place they call home with access to the care and support they need. More people have choice and control over their care and local communities are in the driving seat for delivering the personalised care and support that people want.

Local care economies that bring together those accessing care, innovators, community and public sector groups are collaborating to support those who need access to services. The health and wellbeing of those who need access to care is greatly enhanced. Declining trends in satisfaction with social care have been reversed. The ONS Health Index notes improvements in the nation's health and wellbeing underpinned by improvements in those accessing care and support[15].

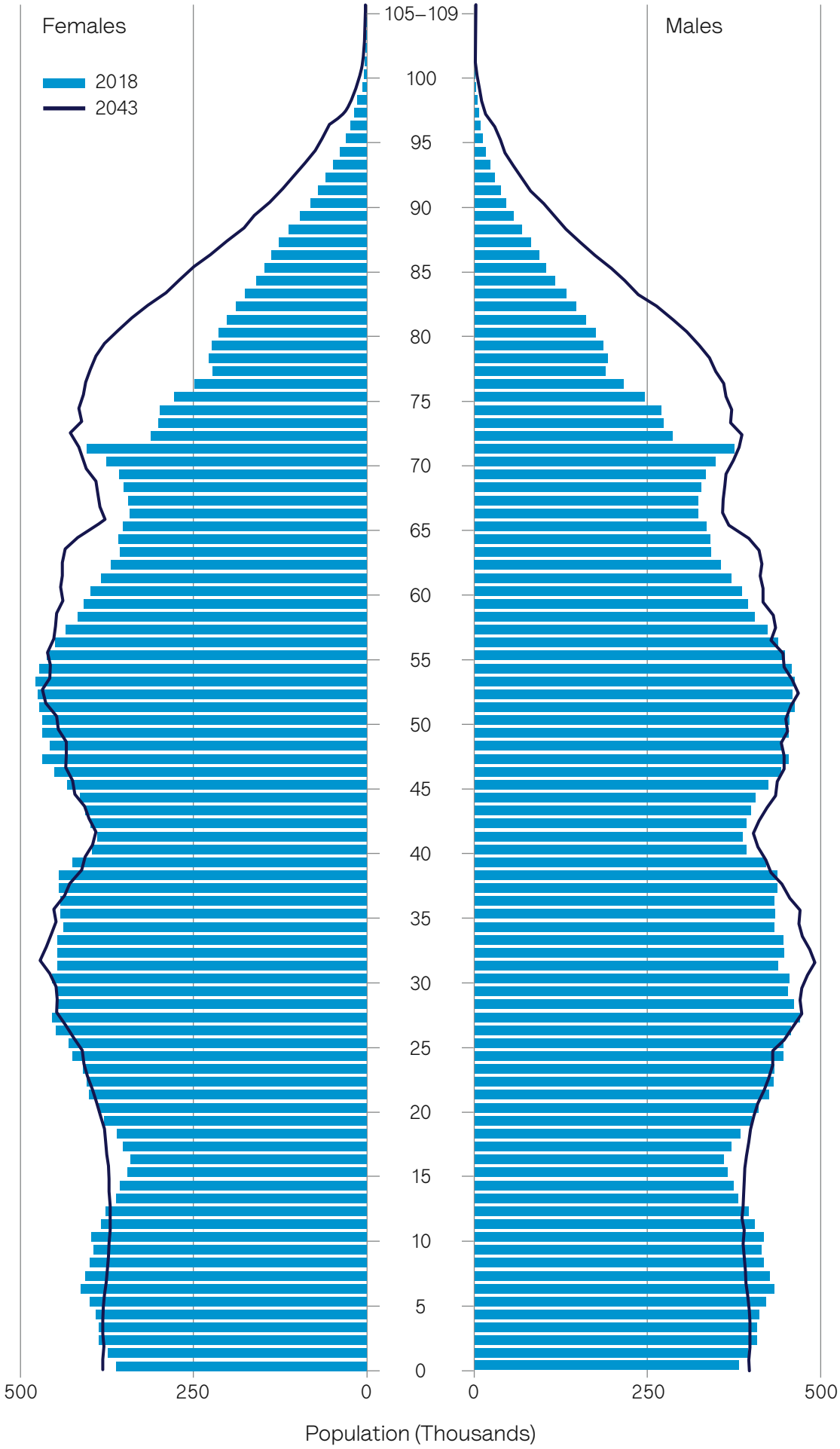
# **Background:** The state of social care

Adult social care covers a wide range of services, care and support. The National Audit Office defines it as "Adult social care (care) covers social work, personal care and practical support for adults with a physical disability, a learning disability, or physical or mental illness, as well as support for their carers. Family or friends provide most care unpaid.[16]"

The King's Fund defines adult social care as: "a wide range of activities to help people who are older or living with disability or physical or mental illness live independently and stay well and safe. It can include 'personal care', such as support for washing, dressing and getting out of bed in the morning, as well as wider support to help people stay active and engaged in their communities. Social care includes support in people's own homes (home care or 'domiciliary care'); support in day centres; care provided by care homes and nursing homes ('residential care'); 'reablement' services to help people regain independence; providing aids and adaptations for people's homes; providing information and advice; and providing support for family carers."

Over 800,000 people receive publicly-funded ongoing long term social care in England, with thousands more private self-funders accessing care. The social care workforce is equivalent in size to the NHS, employing 1.2 million people in full time equivalent roles[17]. 1 in 8 adults are carers, equating to 6.5 million people in the UK, with over 1.3 million providing over 50 hours of care a week[18]. In 2019-20 local authorities spent £16.5 billion on social care[19]. Alzheimer's Society has calculated that 'unpaid carers', or families and friends providing care to their loved ones, are providing care to a value of £13.9billion a year and that this will increase to £35.7billion by 2040[20].

Demand for social care is set to increase as a result of shifts in demographics and an ageing population. In 1991, 15.8% of the UK population was over 65. By 2016 this had risen to 18% and by 2030 is likely to be over 22%[21]. The graph on page 28 from the ONS sets out the expected expansion of the ageing population to 2043[22].


Females
2018
2043
Males
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60
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40
35
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25
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15
10
5
0
500
250
0
0
250
500
Population (Thousands)

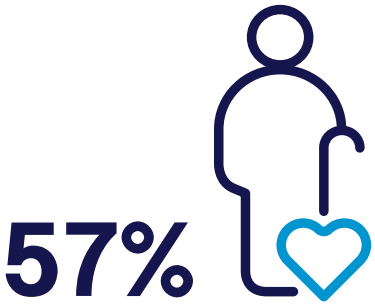
The National Audit Office estimates a:

**29%**

projected forecast increase in adults aged 18 to 64 requiring care by 2038 compared with 2018

**90%**

projected forecast increase in costs of care for adults aged 18 to 64 by 2038 compared with 2018



**57%**

projected forecast increase in adults aged 65 and over requiring care by 2038 compared with 2018

**106%**

projected forecast increase in total costs of care for adults aged 65 and over by 2038 compared with 2018

Academics have noted that demographic shifts will also see rising demand in major areas such as dementia. Currently it is estimated that there are around 850,000 older people with dementia, with an estimated 7.1% prevalence rate among older people in the UK in 2019. Modelling suggests that these numbers could rise to over 1.2 million by 2030, and 1.35 million by 2040. A separate study has estimated that the number of people with dementia will rise to 2 million by 2050[23]. The proportion of people with what is classified as 'severe dementia' is over half, 58% and is expected to pass 900,000 by 2040[24].

The existing system is struggling to cope with levels of demand. According to the National Audit Office, "between 2015-16 and 2019-20, the total number of adults receiving long-term support arranged by local authorities fell from 873,000 to 839,000, within which those aged 65 and over fell 6.6% from 587,000 to 548,000[25]."

There are also a range of other issues highlighted by the NAO in its assessment of the sector:

- Whilst most care provided is classified as good, some 16% of providers require improvement or are rated inadequate
- Many providers are facing financial instability and there is a lack of transparency around provider finances[26]
- Local authorities do not have the levers to effectively shape local adult social care markets
- National oversight arrangements are ineffective at holding the system to account
- The sector faces substantial workforce challenges
- Plans to develop effective future adult social care housing are unclear[27]

## The pandemic

Covid has had a devastating impact on those using social care services and the wider sector. In its assessment of the pandemic, the Health Foundation found that the pandemic had "a major and sustained impact on social care in England. There have been 27,179 excess deaths among care home residents in England since 14 March 2020 (a 20% increase compared with recent years), and 9,571 excess deaths reported among people receiving domiciliary care since 11 April 2020 (a 62% increase). Social care staff have been at higher risk of dying from Covid-19 than others of the same age and sex. The wider health impacts – from reduced access to care, social isolation, increased burden on carers – are harder to measure but also significant[28]."

People with dementia have been particularly badly affected. The largest increase in excess non-Covid 19 deaths between January and July 2020 was in people with dementia. An estimated 27.5% of people who died with Covid 19 from March to June were people with dementia[29].

The care home sector's difficulties have been widely reported, with the Nuffield Trust noting that the pandemic has exposed underlying weaknesses in the sector: "the care sector was already in a fragile state going in to the pandemic and was ill-equipped to cope with the sudden tide of infections. Pre-existing workforce shortages, a vast and precarious provider market, long-standing financial shortfalls, and a lack of robust centralised data about who relies on care created a context in which a response to the virus was difficult to coordinate[30]."

Social care staff have been on the frontline of the battle with Covid 19, suffering significant losses. The ONS data before and during the first 2020 lockdown demonstrated that social care staff had the highest death rates involving Covid 19[31]. The following graphs show the comparatively higher death rates amongst female social care workers.

**Figure 1:** Women working as social care workers had a higher rate of death involving COVID-19 than women of the same age in the population, before the period of lockdown

Annualised age standardised rates of death involving COVID-19, deaths registered in England and Wales between 9 March 2020 and 30 June 2020 and occurred on or before 25 April 2020

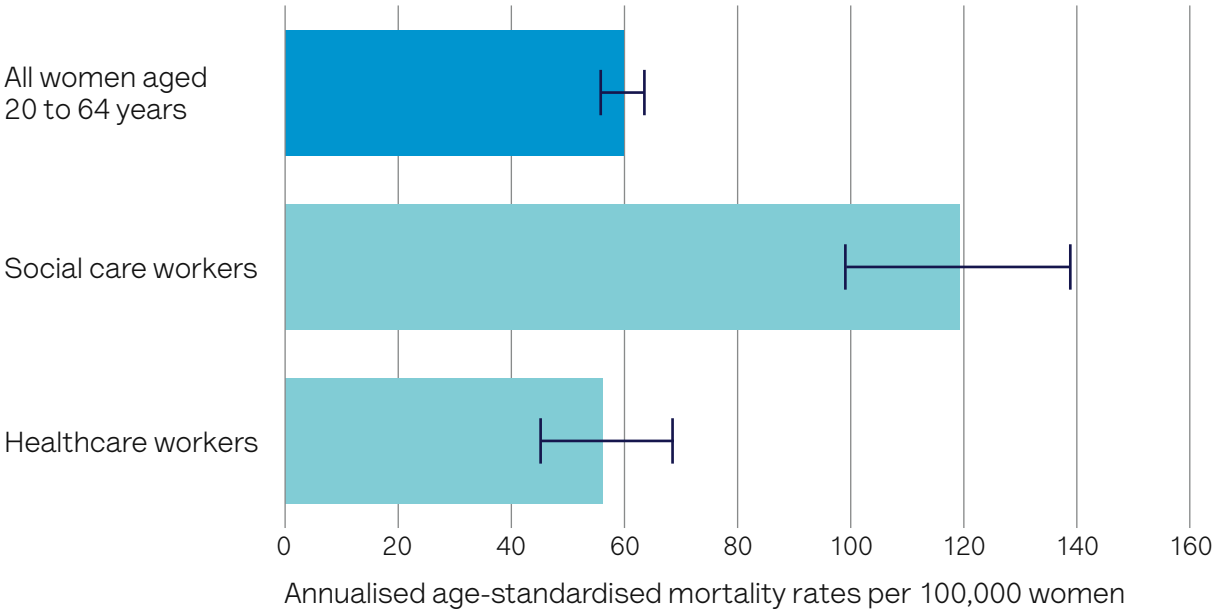
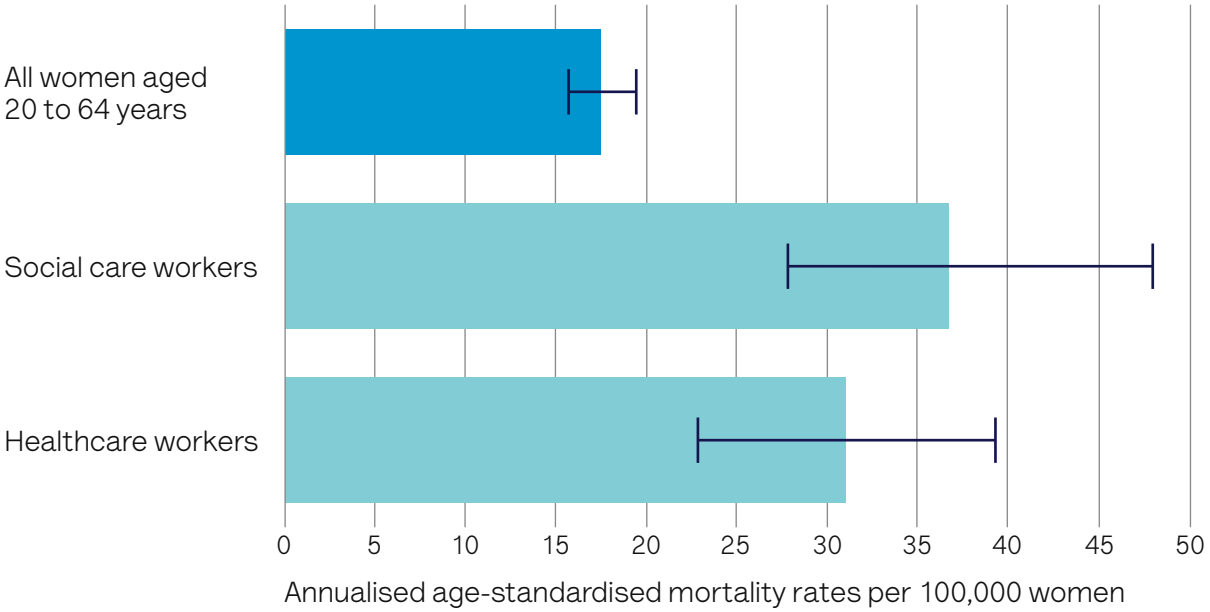



**Figure 2:** Among women, both healthcare and social care workers had the highest rates of death involving COVID-19, during the period of lockdown

Annualised age-standardised rates of death involving COVID-19, deaths registered in England and Wales between 9 March 2020 and 30 June 2020 and occurred on or after 26 April 2020




There are now concerns regarding the medium-term viability of certain providers, with reduced public confidence and occupancy rates creating significant financial difficulties in places. These pressures also place a huge burden on the NHS and unpaid carers. The success of the NHS Long Term Plan is based on pressures from social care not increasing[32].

## The policy environment: case for reform

A combination of rising demand, the pandemic and a system that has lacked investment and strategic reform mean that now is the time for significant change to social care. There have been many false starts. In the past twenty years, there have been some 12 White Papers, Green Papers and consultations, alongside reviews and commissions. Glasby et al label the period since 2009-10 as a 'lost decade' for social care[33]. In a 2010 review for the Department of Health, five rationales for reforming social care were set out:

1. *Maintaining social and public expectations* that the state will provide a degree of collective support to its most vulnerable citizens;

2. Supporting people to have *greater choice and control* over their services, and hence over their lives;

3. *Enabling people to remain independent for as long as possible* so that their needs do not deteriorate into a future/costly crisis;

4. Providing support to those in need so that they can contribute fully as active citizens; and

5. *Reducing some of the negative impacts of poor social care on families* and individuals who care for others[34]

However, by 2019: "there were almost daily warnings of the potential collapse of the current system, severe and adverse impacts on people with care and support needs (and their families), a mounting workforce crisis, the bankruptcy of a series of large care providers, and well-publicised abuse scandals[35]."

In July 2019, on the steps of Downing Street, Boris Johnson said he had a plan to 'fix' social care. The Conservative manifesto included a commitment to a cross party consensus to solve the challenge, and stated that no-one should have to sell their home to pay for care. As yet, no plan has been produced. Government insists that this will be published by the end of the year, and the new Secretary of State for Health and Social Care has labelled social care one of his top three priorities. However, the Government has failed to meet several recent green paper deadlines.

# **A ten-year social care plan:** Delivering for people

Despite the challenging backdrop, a better social care future is possible and now is the time to begin the process of building it.

Analysis of the need for change and a new approach to social care is clear. By 2030 if no change is forthcoming over half a million people in England with dementia will require care home level support. This represents an increase of nearly 170,000 from the numbers recorded in 2019. The number of beds in care homes however is only projected to reach 450,000 by 2030, leaving a shortfall of 50,000 people with dementia without the care they need[36].

This gap needs to be a driving force for real change. Building more personalised, community based and preventative care models will be critical to ensuring people get the care and support they need and want.

Any long term social care plan should have this as a primary objective. A major part of delivering on this will be moving away from traditional ways of seeing and talking about users of social care as 'vulnerable people' and instead approach the challenge by asking questions aimed at eliciting a response that is personal to the individual. This can be as simple as asking 'what matters to you?', and then working out how this can be achieved.

In order to build a successful new approach, there is an imperative to listen to and engage with the views of those who draw on support. There are some good examples already in action for such engagement.

## Social Care Future

Social Care Future have built a new narrative for social care based on the views of those drawing on support. The narrative includes statements such as:

> **"social care is about people having the support to live how, where and with whom they choose to'**

> **"social care draws together relationships and support'**

> **"living how we choose to live is dependent on the strength of the relationships that we have'**

When tested on the public, these statements resonated much more strongly than traditional ways of describing and referring to social care. They can provide a new platform for building wider support for improvements and a higher profile for social care[37]. A recent survey of local councillors found 94% support for the Social Care Future vision[38].

## The Dementia Statements

The National Dementia Action Alliance built a set of 'Dementia Statements.' The Statements, below, are grounded in human rights law. The Dementia Statements are a rallying call to improve the lives of people with dementia and to recognise that they should not be treated differently because of their diagnosis.

### The Statements

> **We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.**

> **We have the right to continue with day to day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.**

> **We have the right to an early and accurate diagnosis, and to receive evidence-based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.**

> **We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future.**

> **We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part[39].**

## Think Local, Act Personal

Think Local, Act Personal (TLAP) is a national partnership of more than 50 organisations committed to transforming health and care through personalisation and community-based support. TLAP has produced an approach to co-production (below) that delivers a more personalised approach to meeting and delivering care and support. It has also built a Make it Real framework to support good personalised care and support for providers, commissioners and people who access services[40].

## TLAP Co-production Framework[41]

1. Co-production must start as an idea that blossoms with everybody involved having an equal voice.
2. Come to the table with a blank agenda and build it with people who use your service, their carers and families.
3. Involve people who use services, carers and their families in all aspects of a service – the planning, development and delivery.
4. In order to achieve meaningful, positive outcomes, everybody involved must have the same vision, from front line staff to management/board members.
5. Start small and build up to bigger projects, letting people lead, not professionals.
6. Acknowledge that a range of skills are needed for co-production.
7. Recruit the right people that support co-production.
8. People who use services, carers and families should be clear about what their expectations are and be fully engaged in the process.
9. People who use services and their carers know what works, so you can't get it right without them.
10. Don't take responsibility for solving every problem—allow the group to find collective solutions

## Barriers and opportunities

However for too many people, their experience of social care and support is undermined by a lack of access to:

- Information
- Choice
- Personalisation
- Support for carers

## Case study – Amelia, Sefton, former carer for her mum

Amelia's mum was diagnosed with dementia seven years ago, living at home with Amelia and her family for most of this period. From December 2018, her mum's health declined, leaving Amelia to often stay up all night by her side. Amelia fought for NHS continuing healthcare funding, which eventually allowed her mum to get some professional care. This only scratched the surface. Before this point, caring responsibilities had fallen completely to Amelia and her siblings. In March last year, her mum was admitted to hospital due to a UTI and subsequent pneumonia. Amelia did not think her mum was receiving appropriate or adequate care in hospital, so fought to have her discharged.

After returning home the UTI came back in June. Amelia spoke to a consultant. They told her to take her mum to hospital. Due to the serious threat of Covid-19 and strict visiting restrictions, Amelia did not want her mum to go into hospital again. She knew it was not the best place for her. She asked if her mum could receive the relevant intravenous drugs at home. The doctor refused due to a local Clinical Commissioning Group policy. She later found out that, had they lived in Liverpool, the doctor would have agreed to it. Amelia also spoke to the GP who responded similarly, so Amelia demanded that someone see her mum at home. She knew what her mum needed but felt like she wasn't being listened to at all.

A nurse came to visit. Amelia's mum was prescribed an increased dosage of an incorrect antibiotic which resulted in additional infections and a superbug called Clostridioides Difficile (C. Diff) to develop. This was an immensely distressing time. Amelia's mum sadly died at home with organ failure. Amelia and her family were left heartbroken. Amelia was angry that her mum had been abandoned by an inconsistent and disjointed care system; one that refused to listen to her or truly value her mum's life.

Amelia says:

> **"I want to make sure this doesn't happen to another family. There's such inequality, and people with dementia are being put at risk and given a death sentence. It was a horrendous decision to make as a family and there shouldn't be a difference in care depending on where you live. It's a total postcode lottery. Having to go through that was so unfair."**

## Access to high quality information

Many users of social care express difficultly in finding the information they need about what they are entitled to as well as what support is available. The system is complex and often impersonal.

One of the main barriers to accessing good information is the lack of a clear route to doing so.

Digital and online information is an increasing source of advice for people regarding their care and support. However, accessing high-quality and verifiable information can still be challenging. Whilst the Care Quality Commission does rate social care providers, its wide remit across health and social care can make navigation of its website and resources difficult. The new CQC strategy is looking at ways to improve its approach to provider regulation and provide higher quality information to the public[42]. Organisations such as Trusted Care that emphasise the personalisation of care needs and seek to connect people with trusted and accredited providers are another example of an organisation trying to close the gap[43].

The NHSX data strategy published in June 2021 included a welcome vision for people to "have access to data on the nature and quality of local care services so I can make better informed choices about my care and preferences[44]." However, the strategy is light on how improvements will be made in publicising and signposting people to high quality information on the type and quality of care and support needs available.

With reform to health service structures, the creation of primary care networks based in local communities, and a focus on social prescribing, there are opportunities to make finding this information easier. Link workers will be especially important here, but their profile is largely unknown to the general public and anecdotal feedback on their effectiveness is mixed. A campaign to not only increase the numbers of Link workers but also evaluate their effectiveness is needed. One way to enhance the value of Link workers is looking to place them within established and well-recognised health care settings such as GP surgeries and pharmacies. A survey in 2018 by the Royal College of GPs (General Practitioners) found that 59% of GPs believe social prescribing not only helped patients, but also reduced their workload by an average of 28%, leading to a call for it to be used more widely[45].

## Case study – Shropshire and Dementia companions

In Shropshire, working directly with people with dementia led to the creation of dementia companions. The Dementia Companion's role includes work to:

- help with planning about future needs
- help the friends and family of the person diagnosed, to be dementia aware.
- encourage social groups to involve people with dementia in activities
- have local knowledge of Dementia Friendly businesses such as taxi-firms, pubs, hair salons, cafes, shops etc. and will be able to promote their access to the person with dementia and their Carers
- promote the importance of ensuring the personal preferences such as when admitted to hospital (for example by using 'This is Me')
- assist carers and others working with people with dementia to develop skills such as approaches to communication, activities of daily living, skill training and activity planning
- remain in place as a point of contact when the person with dementia is in residential care.
- be involved in discharge planning from hospital admissions
- provide the carer of the person with dementia with a level of emotional support, and signpost on to bereavement support

The Dementia Companions have helped more people to live well with dementia.

## Access to choice – personal budgets

Personal budgets are designed to provide users and carers with the freedom and independence to select the care and support they want. Personal budgets can be taken as direct payment or through managed accounts. However, the pace at which personal budgets have been used has stalled. The number of people using direct payments falling from 126,000 in 2018/19 to 123,000 in 2019/20[46]. The fall is part of a recent trend set out in figure 3 by the Kings Fund below.

A review by TLAP of direct payments during the pandemic found that a number of core concepts regarding personal budgets needed to be re-stated as users felt they had been forgotten:

- Independent living and supporting its achievement to enable an equal opportunity to have a good life
- The self-directed support process developed by In Control to articulate the innovation of direct payments
- Personal budgets which built on the In Control self-directed process and made this principle available for all eligible for adult social care
- A shift in thinking about how the health and care system works - from one where people are passive recipients gifted care and support by the state, to one of active citizenship where the state supports people to take control when they need additional support to 'maintain their wellbeing[47]'

Returning to the core principles of the Care Act and driving them forward with renewed vigour should be at the heart of ambitions to see transformation in social care over the next ten years. Alzheimer's Society's report A Future for Personalised Care sets out a number of ways to deliver on this ambition including for Government setting a vision for personalised care to support improved commissioning and enhancing and expanding the evidence base of social care best practice[48].

## Accessing and responding to feedback

In order to ensure that services are delivering for those who use them, it is important for regular feedback to be taken. The Government's Health and Care Bill (2021) includes provisions for new health service structures to engage with the public, and new health systems should set out clearly in their forthcoming plans how they intend to do this, in consultation with local Healthwatch and other community groups[49]. ICS Board representation for social care providers and voluntary groups will ensure the voices of social care are properly included in future discussions about health service priorities and resources.

The National Audit Office notes that at a national level the existing Adult Social Care Outcomes Framework does not adequately "cover all local authority responsibilities for care, nor does it focus sufficiently on well-being and user perspective[50]." NHS Digital has also set out where gaps in the social data exist, noting gaps in assessing unmet need, informal care and care quality[51]. There is an opportunity here to update the metrics within the framework to ensure they capture the experience and wants of those accessing services; including whether care is delivered in places people have requested and level of choice and engagement users experience. NHSX's new data strategy presents an opportunity for such changes to be made. Similarly, the Care Quality Commission, with new powers to oversee local authorities in their commissioning of social care services, should ensure that the views of users and carers are at the heart of their new assessments.

In certain areas of health and social care opportunities should be taken for more focused feedback and surveys on user, carer and staff experience. Technology can make such exercises faster and more efficient to deliver. For example, the World Health Organisation launched a Global Dementia Observatory in 2017, with England playing a leading role in its creation. Over the next decade, the Government should develop plans for a more regular survey of people living with dementia and their carers to support improvements in services domestically and internationally. This could take place annually or every two years and be overseen by a new Dementia Observatory[52]. A model and approach for this could be the National Cancer Patient Experience Survey[54].

The NHS Health and Race Observatory also presents an opportunity for future investigations into ethnic inequalities in dementia care. An NIHR study found that:

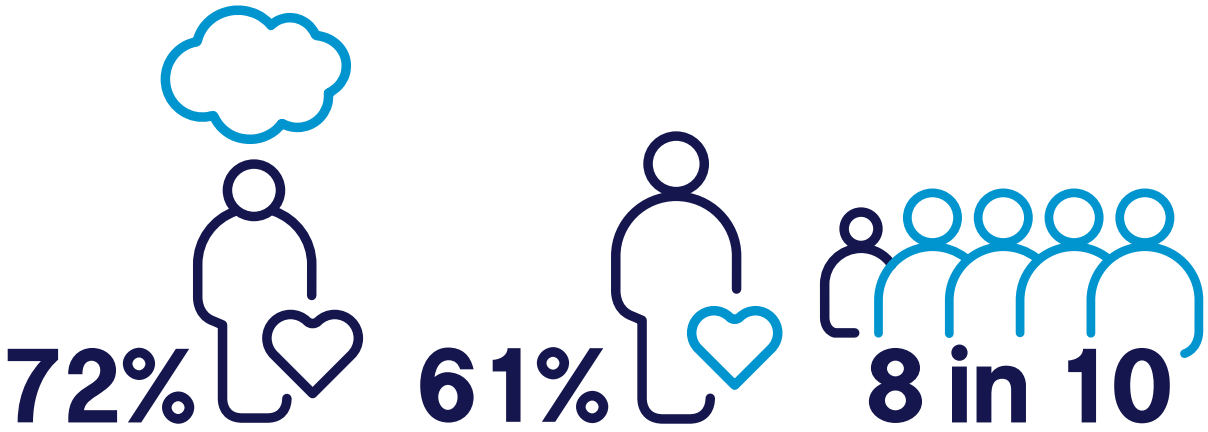
> **"People with dementia from ethnic minority backgrounds face inequalities in diagnosis and access to care, compared with White British patients. A large study in South East London found that at the time of diagnosis, overall, they are more likely to be on multiple medications, but less likely to be taking antidepressants[54]."**


mer's Society

## Access to support for carers

Formal and informal carers play a critical role across health and social care. Carers UK have estimated that 13.6 million people were performing caring duties during the pandemic .

A survey by the charity found that many had seen their own health and wellbeing impacted by their caring responsibilities:




The Alzheimer's Society has calculated that:

- There are approximately 700,000 informal carers of people with dementia in the UK, many of whom are themselves older people with their own physical/mental health issues
- During the first wave of the Covid-19 pandemic, family and friends have spent an additional 92 million hours caring for loved ones with dementia
- Since the pandemic began, unpaid carers have provided £135bn worth of care[57]

An Alzheimer's Society study assessing the support available to carers of people with dementia found many limitations in support and gaps in national data about carer needs. The study set out a set of recommendations to improve the system including for local authorities to capture carer needs in health and wellbeing strategies, early outreach from councils to newly identified carers (within 4 weeks), and the need for proactive carer assessments[58]. NHSX's data strategy presents an opportunity for the NHS and local authorities to tackle such gaps.

As part of post pandemic support for carers the Government should use the Spending Review to introduce improved funding for carer breaks.

## Case study – Nadia, London, person affected by dementia

Nadia's mum was diagnosed with Alzheimer's in 2012 and lives with her and her young family in London. Nadia had to change careers in order to work more flexibly whilst caring for her mum. Nadia juggles parenting, work and caring responsibilities.

The pandemic has been challenging as her mum has got used to the family being at home during lockdown. As restrictions have eased this learnt behaviour has proven disorienting. Nadia believes better support should be more easily available to carers:

> **"My mum was diagnosed in 2012 but we only spoke to a dementia nurse who has been wonderful and a huge help this year. A dementia diagnosis is life-changing both for the person diagnosed and for their family. It feels too often that you are fighting the authorities rather than them being on your side. There needs to be more help and practical tools for carers. We were eligible for live-in care, but were not told. Now we have it we can plan a holiday for the family."**

# A ten-year social care plan: Enablers for change

In order to deliver the changes we want to see, including more personalised care, three major enablers for change need to be addressed: funding, workforce and quality.

# Enablers for Change: Funding

## The long-term funding of social care must tackle three issues

- Fairness
- Sustainability
- Transformation

## A fairer system

If you receive a cancer diagnosis, your treatment on the NHS is rightly free at the point of need. If you receive a dementia diagnosis your care and support could mean you find yourself liable for bills running into hundreds of thousands of pounds for costly and means-tested social care support. Any long-term social care funding solution must tackle this problem urgently.

Fortunately, a reasonably well-trodden and quick solution for tackling catastrophic care costs is well known. As set out earlier, the 'Dilnot cap' legislated for in 2014 (but never enacted) provides a model to restrict the amount of money people need to pay for their care[59]. The cap provides an approach to tackle this problem whilst a systemic, embedded solution to social care funding is worked up and introduced.

## Case study – Jonathan, Surrey, person affected by dementia

With Mum and Dad both working as teachers, they had saved up as much as they could for their future and their care needs, but it was not enough. My brother and I soon needed to rent out Mum's home. But one month's rental of her home, covered less than one week of care home fees.

As we could see that her care home fees were rapidly exhausting her savings, we had to sell Mum's home.

For loved ones such as me and my brother, the care system left us confused and ill-supported to navigate the choices both we, and Mum, had to make, and access the care she so desperately needed .

## Sustainable and secure funding

The cap is only part of the solution to the overall challenge of social care funding. It transfers part of the risk from the individual to the collective, but it does not get any more money into the social care system. More funding is needed to:

- Improve the quality of care that people are receiving
- Increase access to care
- Support carers
- Improve pay, conditions and training and development for the workforce

The ambition for new funding over the ten years should be to deliver care that is free at the point of need for those who need. While this is often looked at as 'free personal care', this should not be seen as delivering more of the same care that we already have based around a list of basic tasks.

Rather the ambition should be for 'free personalised care,' where care is built around the needs and wants of the individual. Social Care Future note that: "genuinely personalised care and support means honouring personhood & identity." The group lists a number of enablers for delivering this including personal budgets, shared lives, community circles, local area co-ordination and wellbeing teams[61].

### What is Personalised care

Alzheimer's Society defines personalised care as: "care that upholds our right to be recognised for who we are, and for our diagnosis not to define or limit the life we lead, as the Dementia Statements show. A more expansive vision for social care that places greater emphasis on personal agency, choice and control, built on the underlying assumption that people are ultimately best placed to make decisions on their care, support and wellbeing. A belief that social care and care and support services are not a destination in themselves but should be capable of supporting people to find purpose, meaning and connection in their daily lives[62]."

Putting social care on a more sustainable footing and delivering personalised care will require a significant uplift in investment, an estimated £7-10bn per year and require political courage to enact[63].

However, the public does support increasing investment in social care. Polling commissioned by Policy Exchange and IPPR in 2020 found that 53% of the public supported increasing investment in the sector after the pandemic. The option with the highest support for raising the funds was through general taxation (39%), with another fifth (19%) in favour of a hypothecated social care tax. Such figures show broad support for a mainstream tax increase to fund social care reform; and would show public support for a mooted national insurance rise to pay for care. The findings also demonstrated a cross party consensus with 45% of Labour voters and 41% of Conservative voters in favour of moving social care onto an even footing with the NHS[64].

There are also likely to be benefits in delivering an enhanced state offer. Currently, funding for social care support is drawn across a range of different schemes led by different agencies and departments – examples include the Better Care Fund, Continuing Healthcare and the Disabled Facilities Grant. In moving to an enhanced state offer there is the opportunity for the Government to review these grants and funding pots and ensure that they are delivering the enhanced personalised care expected.

The improvements in quality of life from more personalised care and support will also yield social, community and economic benefits. Such benefits will include reductions in expensive healthcare setting attendances and for working age adults the ability to fulfil their potential in the labour market.

## Transformation funding

Alongside capping care costs for individuals and delivering a more sustainable system, injections of funding are needed to transform the way care is delivered.

The potential of new technologies to deliver care in places people call their own is transforming the opportunities for new ways in how and where care is delivered[65]. A study by Future Care Capital in early 2021 found 50 start-ups developing home care technology[66].

Within the NHS there are number of different healthcare technology accelerators such as the Accelerated Access Collaborative and the NHS AI Lab. During the pandemic, a one-off set of social care grants, under the TechForce scheme, were awarded to companies who were able to support people shielding during the pandemic[67].

The Local Government Association and NHS Digital have established a Social Care Digital Accelerator in 2020/21 that is supporting three projects. However, the level of interest in the programme is such that over 200 submissions were made.

For social care, Government should support an expansion of the existing digital accelerator to enable a wider set of technologies to be adopted and their use expanded.

In order to benefit from technological transformation, the sector will require new capital investment. The disparate primarily private sector market and its operating model can make securing access to capital difficult. Within the NHS, the Local Improvement Finance Trust (LIFT) has provided organisations with access to capital investment to improve local community and primary care facilities. Local authorities can benefit from the scheme, but maximising opportunities so that social care facilities and new models of social care can be introduced should become 'core business' for the scheme[68].

For Government, there is an opportunity to explore new types of capital incentives for providers to invest in new technologies and ways of working.

A report by ADASS and TEC Services Association recommended the creation of a £450m programme of funding to replace current care and housing technology infrastructure[69]. This should be included as a key part of the Department of Health and Social Care's capital Spending Review bid[70].

The Government could go further and seek to work collaboratively with the social care sector on future financing options for capital and seek to build a 'Sector Deal' which would bring public, private and other funding together to deliver the transformation needed.

When new models, technologies and approaches are found to work it will be critical that they are spread more widely across the country and properly embedded. Dedicated transformation funding should be available to support such activity which could build from existing 'best practice' work such as the Social Care Innovation Network[71].

# Enablers for Change: Workforce

Before the pandemic, there were already rising concerns regarding the social care workforce. In its submission to a June 2020 Health and Social Care Select Committee inquiry, the Health Foundation highlighted the scale of these challenges:

> **"Around 1.5 million people work in the adult care sector. High staff turnover means approximately 440,000 leave their job each year (a third leaving the sector); there are almost 120,000 vacant posts, at 8% a much higher rate than other parts of the economy; a quarter of staff are employed on zero hours contracts; and more and more staff are being paid at or close to the National Living Wage, potentially contributing to increasing vacancy rates. Close to 140,000 additional full-time equivalent social care staff and an estimated 70,000 additional care home places are needed over the next 5 years[72]."**

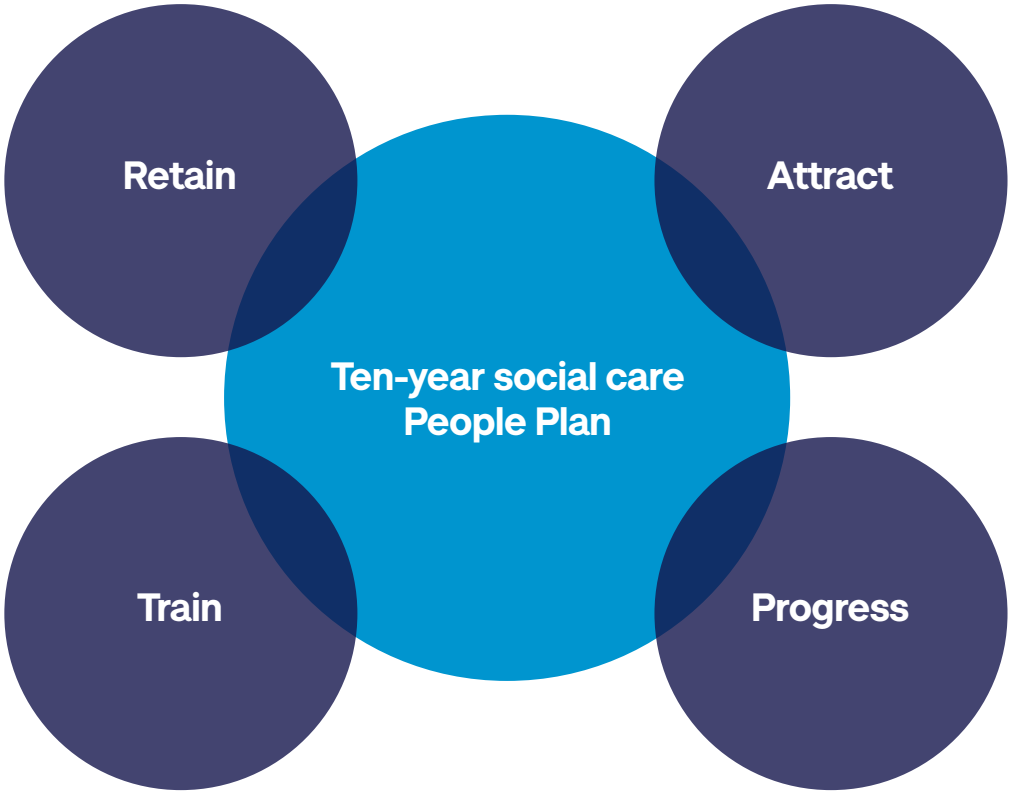
Over 100,000 EU nationals work in social care and there are concerns regarding this long-term pipeline of staff. It is difficult to disaggregate the impacts of Brexit and the pandemic, which have clearly made travel internationally more difficult, but it is clear that many more social care staff are needed.

SCIE estimates that if the adult social care workforce is to grow proportionally to the number of people aged over 65, 580,000 more social care jobs will be required by 2035. If it is to grow proportionally to the number of people aged over 75, this figure would rise to 800,000 jobs[73].

Social care leaders have set out six ambitions for a successful social care workforce strategy:

1. Staff are recognised, valued and rewarded
2. Invest in training, qualification and support
3. Clear career pathways and development opportunities
4. Building and enhancing social justice, equality, diversity and inclusion in the workforce
5. Effective workforce planning
6. Expansion of the workforce in roles which enable prevention and support the growth of innovative models of support[74]

For Government, a long term social care workforce plan should seek to adopt a four-part strategic approach: retain, attract, train and progress.




- **Retaining** staff by tackling reasons for them leaving, including improved pay and improved health and wellbeing support
- **Attracting** the workforce of the future to deliver for those accessing care
- **Training** the workforce and ensuring they have the range of skills to meet the current and future needs and wants of users
- **Progressing** staff through possible new regulation of staff and greater collaboration between health and social care

These four elements should be used to underpin a new ten-year social care People Plan which should set ambitions for expanding and improving the social care workforce.

## Retain

A survey during the second Covid-19 lockdown found decreased wellbeing scores across all social care occupational groups. The study, led by Ulster University as part of a collaboration of academic institutions, found higher levels of depression and anxiety, "which increased from 9% of respondents in the 'likely' to have depression and/or anxiety category and 33% in the 'possible' category to almost 18% 'likely' and a further 22% in the 'possible' category in this second survey[75].

Staff must have access to the support they need for their own health and wellbeing and to ensure they can practice effectively.

## Case study – Sam, Domiciliary Care Worker Manager

Sam manages a team of domiciliary care workers. During the pandemic she has seen the huge pressures on social care staff. Rapid changes to Government guidance, difficulties in accessing the right equipment and worries about the virus have all been hugely challenging. Sam says:

**"Our carers are brilliant and have worked flat out. But many are now burnt out. Our business gave them a bonus at Christmas but Government more widely needs to look at a package that recognises their efforts. There are not enough carers coming through. You become a carer because you care; but we need to do more to get more people to work in social care. Things like campaigns and documentaries can help. At times during the pandemic we felt that community care had been forgotten. We need greater recognition and support for the work we do."**

Turnover in social care roles was already high at 30.4%, though two thirds of job leavers do stay within the sector[76]. The reasons for people leaving the sector are varied, but major drivers include: pay, working environment and an ability to utilise the transferable skills acquired in other sectors such as healthcare, retail and hospitality[77].

New efforts must be made on pay. There is strong support for increasing the pay of care staff[78]. However, the fragmented and diverse nature of the care market makes it very difficult to push through and oversee increases in pay for staff. There is evidence of providers not paying the national living wage for delivering social care services and a number of employees are on zero-hours contracts[79]. The Future Social Care Coalition has set out proposals for bringing social care pay into line over the next Spending Review with Healthcare Assistant Band 3 to provide greater equity between the NHS and social care with regards to pay[80].

For Government the Health and Care Bill provides new assurance powers over local authorities and the commissioning of adult social care. Within the reforms is an opportunity for the Department of Health and Social Care to have greater oversight of the care market and provider practice. A national social care board, as set out by the Health Foundation, would help ensure that sector pay is properly monitored[81]. The Board would be able to track and collect information on provider pay, driving up transparency and enabling more effective enforcement against providers were pay rates are inadequate. The Board should also consider how to more closely align NHS and social care sector pay-scales.

## Attract

The challenges of the pandemic in social care have raised the awareness and salience of the roles and responsibilities in the sector.

The Government has sought to use this opportunity to highlight and attract more people to work in the sector, through campaigns such as ‘Care for Others’, ‘Make a Difference’ and the ‘Everyday is different’ website[82].

As the country begins to fully emerge from restrictions related to the pandemic, the Government should consider a new concerted campaign to attract more people into social care to ensure gaps are filled and care needs met. Such a campaign should also have an objective of increasing the diversity of staff employed in the sector and particularly look at ways to increase the number of men that take on caring roles. Past campaigns have had mixed success, so moving forward, campaigns will need to evaluate what has worked well and less well during previous initiatives, including how the sector has been portrayed and how campaigns have been funded.

A positive campaign is even more needed to attract people into working in social care, particularly given worries about the possible impact of mandatory Covid vaccinations on numbers of care staff[83].

If successful, such an approach will bring wider benefits to regional economies. The health and social care sector is one of the largest employers in most parts of the country and can act as a strong anchor for local economic activity. Previous research by Future Health found that with the right conditions, by 2030, 750,000 new jobs could be created in the healthcare sector across the UK[84]. The Centre for Progressive Policy has similarly noted the regional opportunities of investing in the care workforce: "unlike some sectors, such as financial or IT services, social care is present throughout England. Across the North of England alone, there were more than 330,000 jobs providing direct care in 2019/20, with an estimated 20,000 vacancies at any one time[85]."

The ambition to deliver more care in the community and in people's homes needs to be accompanied by a growth in staff that can provide the necessary support for those needing to access care.

The Government and the NHS have made welcome commitments to increase the number of Link workers as part of efforts to expand 'social prescribing' in coming years. Social prescribing involves helping patients to improve their health, wellbeing and social welfare by connecting them to community services which might be run by the council or a local charity. For people with dementia and their carers, such support can be vital, particularly in referring people to local community support groups.

The National Association of Link Workers sets out the role link workers play including providing: "practical support or information about housing, debt, or benefits, signposting/ referring to activities, community groups or activities that the service user might like to go to while maintaining a supportive, compassionate, non-judgmental, caring and empathetic ear[86]." Link workers are expected to make strong links across health and social care and skills expected include "active listening skills, person centred skills and empathy skills[87]."

However, anecdotal feedback indicates that access to Link Workers is both varied and of mixed quality. Tackling this as part of the future plans should be a priority for the Department of Health and Social Care, as well as for NHS England as part of its further work on the People Plan.

## Train

There is also a need to ensure social care staff have access to training and development opportunities to further their careers and improve the quality of care delivered. In certain areas, proper training is not being provided. For example, Skills for Care have recorded that only 44% of care staff have any form of training in dementia . Social care staff should have tier 2 training in the Dementia Training Standards Framework to support the delivery of more personalised care for people with dementia.

Training is particularly important for developing digital skills. A rapid evidence review by SCIE found that Covid-19 has led to a significant impact on the demand for digital skills in social care. SCIE note that digital skills in the sector are difficult to assess, but are broadly seen to be improving[89]. However, the report also notes that there is likely to be significant work needed in order for the sector to benefit from a range of new technologies "across problem solving, use and management of data, communication, security and AI and robotics[90]."

Research by Skills for Care has demonstrated the missed opportunities from employers in not using the existing digital skills of staff. Skills for Care found that whilst "74% of staff have a personal smartphone, but only 20% actually use their personal phone for work purposes. We also found 45% have a tablet device at home compared with only 8% having a work tablet. This suggests social care organisations aren't always utilising the digital skills of their staff in the workplace, or making best use of the technology available"[91].

Some of the largest barriers to staff training and development are resources and time. Government support can help tackle these issues. At the upcoming Spending Review, Government should ensure that it continues to invest in the training and development of the social care workforce. The Workforce Development Fund is one model for doing so, and is a place where increased investment should be targeted: an evaluation found that 92% of employers who accessed the fund saw an improvement in care quality as a result[92].

## Progress

The pandemic has highlighted the vital role played by staff in social care, and this value now needs to be recognised. One way to deliver this is through enhancing the professional regulation of social care staff. There is the option to formalise regulation fully through a register as happens in Northern Ireland. Alternatively, Government could adopt a less onerous process, where a 'licence to practice' is established. It is hoped that in formalising the processes for practicing social care, the value and attraction of the sector will grow and that this will in turn support retention, which is a major challenge (see above). Government should consult with the sector before making any advances in this area to assess the impact of any such changes.

It is also anticipated that this would have wider benefits, including defining what support workers do, and enabling greater collaboration and ease of working with registered nurses in healthcare settings[93]. It could also help underpin greater integration of the workforce across health and social care, that could have positive capacity and user benefits[94]. Such collaboration would only be enhanced by moves to deliver more equitable pay for relevant NHS and social care staff.

Alongside this, however, it will be important that new regulation is used to deliver improved personalised care. To do this, the workforce need to be empowered and supported to deliver the highest quality care, particularly in not being constrained through contracting and care models. Holland's Buurztog model,[95] which is also being introduced in parts of England, provides a model for how to do this. The model starts from the client perspective and works outwards to assemble solutions that bring independence and improved quality of life, as set out on page 61:

## Case study: Buurztog Model

The King's Fund notes that the "Buurtzorg model of care, developed by a social enterprise in the Netherlands in 2006, involves small teams of nursing staff providing a range of personal, social and clinical care to people in their own homes in a particular neighbourhood. There's an emphasis on one or two staff working with each individual and their informal carers to access all the resources available in their social networks and neighbourhood to support them to be more independent. The nursing teams have a flat management structure, working in 'non-hierarchical self-managed' teams. This means they make all the clinical and operational decisions themselves. They can access support from a coach, whose focus is on enabling the team to learn to work constructively together, and a central back office[96]."

Camilla Cavendish adds that the model

> **"lets nurses – not some remote, cost cutting manager – decide what is right for each of their patients[97]." Cavendish adds that this empowerment has seen "nurses come out of retirement to join it, so enthusiastic are they about the philosophy[98]."**

# **Enablers for change:** Delivering high quality, personalised care

For a long term social care plan to be deemed successful, it will need to see an improvement in the quality of care being delivered, registered in the feedback of those receiving it.

A recent report by the King's Fund recorded a small and long term decline in satisfaction with those accessing publicly funded social care[99]:

"The percentage of people saying they were 'extremely satisfied' or 'very satisfied' with their care and support fell very slightly from 64.3 per cent to 64.2 per cent. What is the long-term trend? There has been a slight overall fall in the number of people satisfied with their care and support – in 2014/15, 64.7 per cent expressed satisfaction, but by 2019/20 this had fallen to 64.2 per cent[100]."

There are a number of opportunities over the next ten years to address this and make improvements in the way care is delivered:

- New models of personalised care
- Reforming the care market
- Building deeper partnerships across the public, charity and private sector

## New models of personalised care

Technology can be a great enabler for higher quality and more personalised care. A report by ADASS and TEC Services Association found that 76% of social care providers say that using technology leads to better outcomes, with 66% saying that technology frees up social care staff time[101].

## Case study – Refresh by How do I?

How Do I? is an assistive technology company that want to help people with dementia live independently at home for longer. They have developed 'Refresh', which is a mobile video support tool that can link helpful personalised videos to objects in the home. These videos can help with remembering how to complete a task, or capture memories of activities you've taken part in and don't want to forget. Refresh has been recognised by industry experts and people affected by dementia through two awards programmes, the AAL Smart Ageing Prize and the Essex Challenge Dementia Programme. Further evaluation of the technology is continuing to support effective deployment and user engagement.

In order to capitalise on the opportunities new technologies present, a number of issues need to addressed:

**Digital inclusion –** access to technology is not universal, and technology-enabled care needs to be delivered in consultation with users and carers. For Government, any long term social care plan will require cross departmental working between DHSC, DCMS and Cabinet Office to set out a roadmap to eliminating digital exclusion by the end of the decade

**Standards –** evidence presented at the roundtable series highlighted the difficulties of ascertaining the quality and standard of new digital applications for supporting people with care needs. NICE and NHSX should explore a suitable process for kite-marking and accrediting certain digital social care interventions to support commissioners, users and carers in choosing the highest quality applications that best suit their needs

**Integration –** the new data strategy from NHSX sets out a path for better and more co-ordinated healthcare data flowing between different organisations across health and social care. This ambition for better data, intelligence and information can support people to live the lives they want to lead independently and begin to position services as enablers for delivering a more proactive and preventative set of care models. It is critical that this integration is not just delivered at system level, but at person level with improved access to digital healthcare records across health and social care. ADASS and TSA have advocated a 2025 timeline for delivering this.

**Evaluate and scale –** ensuring that the best innovations are scaled so that greater numbers can benefit from them should be a priority in the next decade. Establishing clear evaluations and standards for new technologies, funding and support for implementation and better information for users and carers can all support improvements in the uptake and scale of new technologies in social care.

The work of SCIE and Social Care Future through their Innovation Network has identified seven factors that are particularly critical for scaling innovation in social care:

- Acknowledging and engaging with complexity
- The complexity of the social care landscape
- Funding to support scale and spread
- Recruitment and turnover of staff
- Level of risk aversion and defining 'acceptable' risk
- Engagement and co-production
- Evidence generation and evaluation[102]

If an ambition for more care to be delivered at home is to be realised, then both new and existing homes need to be built or have an ability to be easily adapted to support people with care needs. This 'care ready' mindset must be central to the Government's house building and planning reforms. One of the joint winners of the Government's Home 2030 Design competition was Connector Housing.

Connector Housing proposed "a flexible and adaptable system for age-friendly, multi-generational housing and neighbourhoods. It proposes varying densities of houses and apartments, with a variety of site configurations, vertical heights, external appearances and internal layouts that can be adapted to respond to changing occupant needs[103]."

Housing LIN has a five-point roadmap towards improving and increasing housing for an ageing population including local planning, improving the guidance on lifetime homes, promoting the wider economic benefits to the housing market of housing for older people, new finance options and investment to support people to move and strong standards of regulation[104].

## Reforming the care market

The difficulties faced by care homes during the pandemic have been well documented. These challenges have led to a drop in public confidence. A survey from 2020 found that 20% of people were less likely to seek care for themselves or family in residential care[105]. Care home occupancy rates have also fallen from 87% to below 80%[106].

However, forecasts are that the sector will recover to pre-pandemic levels by the end of 2021[107]. Medium term there are still expectations that the number of elderly care beds will fall by 16,000 by 2024[108]. There are also concerns regarding the post-pandemic viability of areas of the sector.

With the number of people needing care rising, there is a need to both ensure that the care home market is delivering high quality care but also that other models of care delivery outside of care homes are actively encouraged.

In their 2021 report on this subject, the Nuffield Trust found a number of failures with the current social care market including downward pressure on fees creating uncertainty and a lack of levers to deliver market improvements[109].

One of the main challenges identified was in the difficulties for councils in shaping a local provider market:

> **"Councils' efforts at shaping and developing the provider market to suit the needs of the local population are hampered by a lack of a reliable data about providers and the people who use care services. A focus on balancing the annual budget, coupled with losses of experienced staff, has driven a short-termist approach to purchasing individual care packages. This manifests in highly transactional relationships between providers and their commissioners and a lack of focus on innovation[110]."**

The National Audit Office in its assessment of the market has noted the fragility of the sector and the impact of Covid 19 in particular: "CQC's latest analysis found that, despite COVID-19, revenue and profitability among large providers had remained relatively stable due to government support. However, it warns that ongoing support could be required in 2021 if care home admissions remain low or costs inflated[111]."

The Government should commission a review of the adult social care market to examine how the market can be invigorated with a wider plethora of providers that can meet the different needs and wants of those accessing care. The review should also consider ways to improve transparency regarding provider finances. It should also consider the ways in which regulatory frameworks and approaches are operating to ensure that they are encouraging the right market and ways of working amongst commissioners and providers to flourish.

This review should coincide with a post-pandemic assessment by local authorities of their local health and care needs through updated Joint Strategic Needs Assessment and Joint Health and Wellbeing Strategies. Such updates will be critical for post pandemic health and social care planning.

## Building deeper partnerships with the public, charity and private sectors

If social care is going to be more personalised and designed around the person, bringing important services more closely together to ensure individual needs are met will be critical.

With NHS structures changing through the creation of ICSs, there is an opportunity for local government and social care commissioners to work more closely in partnership with the NHS. This should particularly help tackle the problems and issues for people moving frequently between NHS and social care settings, such as those with dementia. To do this, local authorities should have parity with NHS organisations in the management of healthcare services in their regions.

The creation of ICSs presents a positive opportunity for closer collaboration between different partners across health and social care. However, it also poses a risk that power structures and accountability are diverted to larger regional structures and point upwards to national government rather than down to the communities and people they are there to serve. Provisions in the Health and Care Bill for greater CQC oversight of local authorities could bring welcome scrutiny around practice, but this needs to balance attempts by local government at innovation and locally tailoring of services for local populations. The Department of Health and Social Care needs to make sure its accountability plans address this balance sufficiently.

To truly deliver a more personalised system will require a dissolution of traditional silos and boundaries between public, private and the voluntary sector and adopting asset-based approaches. These approaches will see an enhanced role for communities and 'place based' models that can use a range of local networks and community services to improve people's health and well-being.

## Case study – Anthony, Epping Forest, person affected by dementia

Ant was unable to continue to care for his mum who had dementia and he needed help with her personal care. In 2020, she spent six weeks in hospital, where she contracted Covid. Despite raising concerns that he couldn't look after her at home, that's where she ended up returning to. Only a few days later she was back in hospital as her condition worsened. Neither social services or the NHS wanted responsibility for her care.

Discussions around care home placements were escalated and she eventually moved into one under the six weeks NHS provision. Shortly after having moved into the care home, Ant's mum passed away. Ant's main issue with the system is there is no joined up thinking between NHS and any of the care organisations:

> **"no one talks to each other, or at least that is how it seems. As a carer, at every stage I'd spend hours on the phone trying to facilitate things, find out information and keep in contact. I felt I was doing more work than what I was getting from the professionals. This is where I see the system breaking down for families. I know Covid has been really difficult for the NHS and social care but it does feel like they have forgotten about people's next of kin."**

## Asset based approaches

SCIE has built a five-part model for delivering on an asset based approach:

**1.** Change narrative

**2.** Map assets

**3.** Connect assets

**4.** Grow assets

**5.** Monitor and learn[112]

Reflecting the need to move beyond silo-ed working, the National Development Team for Inclusion has set out principles for how effective commissioning should be conducted:

- It needs to be coproduced with communities;
- It needs to follow an asset-based approach;
- There must be a desire and space for creative thinking;
- Decisions need to be driven by a strong evidence base;
- Processes must be to support outcomes and be as light touch as possible;
- Budgets must be place based and;
- It must deliver value for money[113].


# Conclusion

> **We all want to live in the place we call home with the people and things that we love, in communities where we look out for one another, doing the things that matter to us[114].”**

This long term plan for social care started with the above vision for a better social care system from those who draw on services.

By looking at social care differently, we can transform it in new and exciting ways, moving away from rationing support for a perceived group of vulnerable people to a new model that sees everyone getting the care and support they want, where they want it.

Delivering on this will see social care recast as an enabler for supporting health and wellbeing, reducing inequality, regenerating local communities and economies, and contributing to ambitions on new housing and reducing carbon emissions.

After 30 years of inaction, politicians now have a clear mandate to act. They should launch a new public conversation on social care backed by a long term plan supported by the enablers of increased funding, workforce support and new models of personalised care and support.

Doing so will mean the 2020s are not a lost decade for social care but a decade of hope, change and better lives.

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