



# CARE AND SUPPORT REIMAGINED

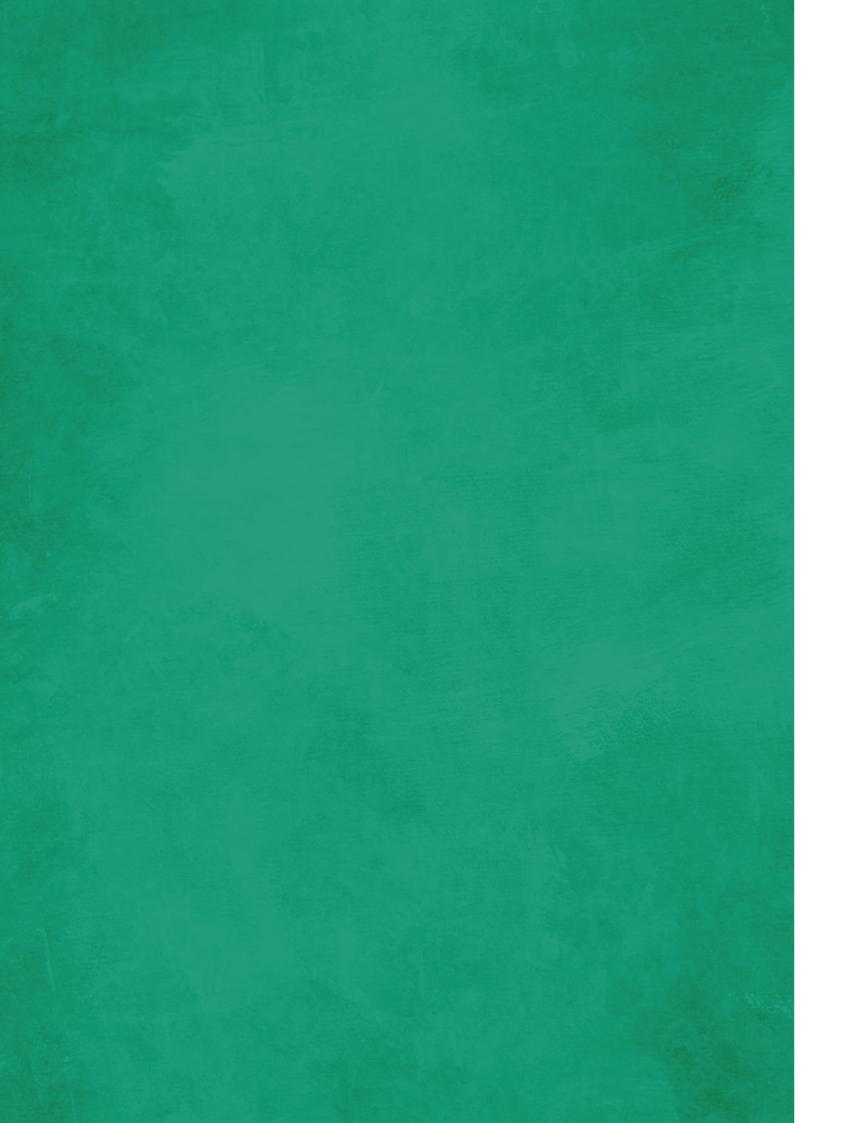
A National Care Covenant for England



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# **FOREWORD**

# by the Archbishops of Canterbury and York





This report is a timely, hopeful, and welcome intervention on the future of social care. The Commission has consulted widely, drawing on the expertise of the Commission Members, to make thoughtful recommendations on a policy area in which the national debate is often narrowly focused, short-term in outlook, and

lacking in wider vision. The report is a clear Christian vision for an issue which affects every person. It seeks to set a path towards a country which gives every person equal dignity, regardless of capacity. In so doing it reflects Christ's command to love one another and the beatitude "Blessed are the meek, for they will inherit the earth." (Gospel of St Matthew 5:5). Therefore we are called to see that those who are weak in our eyes are often those from whom we receive blessing and who offer us an example, Jesus said "Let the little children come to me; do not stop them; for it is to such as these that the kingdom of God belongs. Truly I tell you, whoever does not receive the kingdom of God as a little child will never enter it." (Gospel of St Mark 10:14). For those of all faith and none the power of valuing those outwardly powerless is a test of a society that acts well.

The vision offered here requires a fundamental reorientation of our priorities and direction. Jesus Christ offers us life in all its fullness (John 10:10), and so we strive for a society in which no one is held back or disregarded, or treated as surplus and 'just a burden' because of their age or ability. We stand with the Commission in its call to rethink attitudes towards ageing and disability within every aspect of our society – including churches – recognising that every single person has equal value and dignity, and must be treated as such. Whilst changes are proposed to the social care system, with the long-term aim to make social care a universal entitlement, reform alone cannot bring about the change we seek. At the heart of this report is a deeply Christian understanding of what it looks like to live together in community, with people caring for and supporting one another in relationships characterised by mutuality and inter-dependence.

The Commission offers a vision of one-another care, where we have a better sense of what we should do for each other in communities and neighbourhoods, find agreement about where different responsibilities lie, and build long-term networks and associations that will allow people to flourish. The development of a National Care Covenant, proposed by the Commission, is the beginning of a wider process in which we seek to realise this vision.

We offer this document with great thanks to the Commission for their timely and excellent work. It comes with much humility as what we hope will be a gift at a time of great need, provoking debate, deepening compassion and challenging utilitarian or consequentialist and individualised visions of what it is to be human in this country today.

Archbishop Justin Welby & Archbishop Stephen Cottrell

# 1. THE FOUNDATIONS **OF OUR VISION**

# 1.1 Background to the Commission

Launched in April 2021, the Archbishops of Canterbury and York tasked the Commission with developing a radical and inspiring vision, drawing on Christian theology and tradition, that reimagines care and support. The Commission's origins lie in Justin Welby's 2018 book, Reimagining Britain: Foundations for *Hope*, in which he wrote the following:

'Caring equally for the health of all, regardless of perceived economic or societal value, is a clear sign of our values... The lifeboat of social care appears to be adopting a class - and wealthbased preference system. It no longer reflects a commitment to the common good, or solidarity between generations and between the rich and the poor. It is not consistent or resilient, or – on its present basis – sustainable. A reimagination of Britain as a country in which human beings flourish has to put high-quality social care, public and mental health at the heart of its objectives.'

The Commission was therefore tasked with reimagining care and support in a way that addressed the needs and concerns of everyone involved: people who draw on care and support; people who work in the social care sector; people who care for their family members, friends, and neighbours.

The Commission was led Dr Anna Dixon MBE, who served most recently as the Chief Executive of the Centre for Ageing Better,

and a Co-Chair, the Rt Revd James Newcome, Bishop of Carlisle and the lead Bishop for Health and Social Care in the House of Lords. Its membership drew on a range of experience and backgrounds, including people with lived experience. The Commission's full terms of reference and membership can be found in the Appendices. Whilst the Commission recognised the importance of children's social care, assisted dying, palliative and hospice care, they were considered to fall outside of the Commission's remit.

Over the last 15 months the Commission has engaged extensively with a wide range of people and organisations involved in social care through meetings, visits, a Listening and Engagement Exercise, and a virtual summit to test out early conclusions.¹ This work is described more fully in Appendix 1. The Commission has given particular weight to the views of people who draw on care and support, and to unpaid carers. Their experience has been influential in shaping the Commission's thinking and recommendations. In embarking on this Commission, we were urged by Professor John Swinton to be both tough minded and tender hearted; citing Martin Luther King "We must combine the toughness of the serpent and the softness of the dove, a tough mind and a tender heart.". And so it was that we have sought to bring these two attitudes of heart and mind to our work.

# 1.2 What is care and support... and why it needs to be different

Everything we have heard, and all the evidence we have considered, has left us in no doubt that a fundamentally different view of care is needed based on the realities of the lives we lead in the 21st century and the very wide range of care and support needs that most of us will have at some point in our lives. Many of us will experience poor health and disabilities, sometimes from a very early age or even from birth. As we live longer, how we live with frailty and dementia later in life is a growing challenge. At any age, life-changing accidents or other adversities, such as poor physical health, family breakdown, mental health difficulties, or dependency on drugs

and alcohol, can plunge people into crises. The Commission has a vision of care and support that enables everyone to flourish, no matter their circumstances.

'Social care' is not widely understood. The words used to describe it have changed many times over the years. From the 1940s right up to the 1970s, 'welfare services for elderly and disabled' was the official description. A big reorganisation in 1970 heralded the new 'local authority personal social services', supplanted in recent years by the broader phrase 'care and support'. Social care is now widely used as the shorthand term. This



<sup>&</sup>lt;sup>1</sup>https://www.churchofengland.org/about/archbishops-commissions/reimagining-care/archbishops-commissionreimagining-care-listening



changing nomenclature shows the difficulty of pinning down a clear definition of social care that everyone understands and agrees with. Over the years, most definitions have emphasised practical help with washing and dressing, getting in and out of bed, using the toilet and with eating and drinking – in the jargon, 'activities of daily living'. For many older and disabled people, life would be almost impossible without this essential lifeline of personal care. But people have wider social and psychological needs too. In 2014, the Care Act was meant to place the wellbeing of the individual as the new and broader driving purpose of social care. Despite good intentions, services have continued to be rationed ever more tightly to those with the highest essential needs and the lowest financial means. Care providers are struggling to recruit enough staff. Waiting times to get care are growing. The general public perception is that social care is mostly about people with very intensive personal care needs, typically provided in care homes, even though most people get support in their own homes.

The starting point for a reimagined vision of care should recognise the sheer diversity of these individual needs and circumstances. The Commission's view is that supporting people to exist, through basic personal care, is not sufficient to attend to the deeper purpose and meaning of our lives, including our spiritual needs. Instead, the central aim of social care should be to enable people to live the best lives they can, recognising that each of us is individual and unique. That is why throughout this report we refer to 'care and support' to denote a wide range of activities that could involve not only help with personal care, where that is needed, but social and emotional support; help to participate in work, training and education; to engage with friends, family and social networks; to contribute to your local community,

including, if you are a person of faith, to practice your religion, and to have fun. The sources of this support can be many and varied, not limited to statutory care services friends, relatives, neighbours or paid workers, social enterprises, businesses large and small, community organisations, charities as well as social services. Other support might include transport and housing adaptations. In short, good care involves all of us.

Social care is not an end in itself but the means to a better life. Our vision of reimagined care set out in this report, therefore, is about supporting active citizenship. It is built on the bonds of mutual interest and inter-dependency that define our common humanity, acknowledging that most of us will give and receive care and support during our lives. The right we have to good care comes also with the responsibilities we owe each other in how that care is provided and paid for. It is a vision that demands a far more radical and ambitious set of changes than the very limited proposals put forward by recent governments.

Our central ideas involve:

- · A revolution in our attitudes towards care.
- · A social covenant that sets out the role and contribution of people, communities and government and clear expectations of what support should be available.
- · A radical redesign of the system that puts people in the driving seat in shaping the support they need.

These ideas are underpinned by our thinking about the theological basis of care and the importance of values in driving a reimagined approach.

# 1.3 Theology and values

# Taking a theological approach

Some may ask what theology has to say about care and support. It turns out quite a bit and we have sought to thread theology throughout our deliberations.

**WE HAVE CONSTANTLY ASKED THE QUESTION: 'HOW DO WE UNDERSTAND** THIS SITUATION IN THE LIGHT OF WHAT WE KNOW **ABOUT GOD AND HUMAN BEINGS?' THEOLOGY HAS** NOT BEEN AN ADD ON.

Our terms of reference were clear that in developing a vision for care and support in England we should "draw on Christian theology and ethics". We have understood this in a very straightforward, practical manner. We have constantly asked the question: 'how do we understand this situation in the light of what we know about God and human beings?' Theology has not been an

add on. It has come to light in different ways in all our conversations, even if we may not have always foregrounded it. To reflect this we have included throughout the chapters of the report short boxes which give some theological reflection on the subjects under consideration. We would encourage those reading this report, even if you are of another faith or none, to take time to read these. They give some insights into the fresh perspective that those of us on the Commission felt we gained from looking at these issues through a theological lens.

# **Our beginnings**

Perhaps the most fundamental aspect of Christian theology that underpins everything in this report is the belief that we are all made in the image of God. Every one of us bears God's likeness in ourselves, hard though it may sometimes be to detect. It takes us back to Genesis (1:27) - the Creation story, in which 'God created humankind in his image, in the image of God he created them; male and female he created them.'

# A Note on Ethics

At its most essential, Christian ethics is the study and practice of how we apply the teaching and example of Jesus in making good moral, political and social decisions, both personally and corporately. As such, it has much in common with other areas of theology, particularly practical theology. Any principle, policy or practice that conforms to Christian ethics must both be based on the person of Christ and result in positive practical action. At the same time, to be fully ethical, a Christian ethical policy must be capable of resulting in actual application. In pursuing this goal, Christian ethics (in the words of Professor Nigel Biggar) must always be authentically Christian although it does not always have to be distinctively so. By adopting this approach common ground can be found with people of other faiths and none in furthering the common good.

**WE ARE VALUED NOT FOR** WHAT WE PRODUCE, BUT FOR WHO WE ARE. THIS IS WHY WE CAN SAY TO **EVERYONE, WHOEVER** THEY ARE AND WHATEVER THEIR CIRCUMSTANCES, **'IT'S GOOD THAT YOU EXIST -**AND I'M GLAD YOU'RE HERE'.

The idea of 'Imago Dei' – that all human beings are created in the expressed image of God – leads us to recognise each other as a gift. God gifts life to human beings and human beings offer the gift of value and welcome to one another. We are valued not for what we produce, but for who we are. This is why we can say to everyone, whoever they are and whatever their circumstances, 'It's good that you exist – and I'm glad you're here'. This is countercultural in a society which values people as economic units who are valued according to their productivity. As we

embarked on the work of the Commission and discussed the terms of reference for our work, board members of a large care provider pleaded for an approach which values people for who they are – not for what they 'produce' or (in a material sense) 'contribute'. "Please", they said, "can we honour people who are old or disabled, rather than regard them as an inconvenient burden. Please can we see them through new eyes: as assets, not economic units."

Christians also believe that the ultimate expression of 'Imago Dei' comes with the Incarnation, that is God taking on human form in the person of Jesus, who is – in the words of St Paul (Colossians 1:15) 'the image of the invisible God, the firstborn of all creation'. The life and actions of Jesus therefore also provide a model and guide for how we should live and indeed care for one another. This leads us to the second of our beginnings. Jesus' commandment to love your neighbour as yourself (Mark 12:31).



In many cultures and faith traditions there is a shared idea of the importance of doing good to others and with others. It is therefore not surprising that many caring organisations have their roots and origins in church or faith communities.

These two ideas: that we are all made in the image of God and therefore of equal value and that we are called to love one another, provide the beginnings from which our reimagining of care and support has grown.

Our goal in one sense then is the rehumanising of care – helping people to re-imagine it through the lens of human value. While this does require consideration of politics and economics, it also requires a complete revision (re-imagining) of how we look at and think about ourselves and those around us.

#### **History**

The identity of Christianity as a caring religion stretches back into the Old Testament, and its constant imperative to care for the most vulnerable – the orphan, the widow, the alien (that is, those without existing networks of protection and care). The early church continued this focus with their work in the Roman Empire providing care and support to those who lacked supportive family or social networks. The need for this help was and has remained great, prompting the foundation of formal faith-based organisations dedicated to care and support.<sup>2</sup> Some of the oldest of these still in operation, such as St Thomas' and St Bartholomew's hospitals in London, are almost one thousand years old. There are records of similar organisations founded

elsewhere in the world by Buddhists, Jews, and Muslims.

Even after the advent of modern medicine transformed the role of hospitals towards acute medical care, the need for basic care and support remained and the church continued to provide it. In Victorian times, for example, the fear of the workhouse meant that poor people living with disabilities or infirmities did their best to steer clear of institutional help. The biggest source of alternative assistance for these people, and also those suffering with illnesses, came from roaming clergy who would deliver personalised packages of spiritual support and physical care (both rudimentary and medical) with an additional concern for promoting the social integration of those they helped. This work, termed 'district visiting', later developed into the practice of district nursing that we know today.3

The foundation of the welfare state (itself influenced by Christians such as Archbishop William Temple and R H Tawney<sup>4</sup>) has been another seismic shift in the provision of care and support in Britain, although its influence in this area has been complex. The vocation of the church to provide care and support has continued to be expressed through the work of numerous voluntary groups such as the Methodist Homes Association (MHA) founded in 1943, the Abbeyfield Society (1956), and L'Arche in the UK (1973). Carers UK was born out of a 1963 campaign by Rev Mary Webster to increase awareness of the difficulties of unpaid care. The recent roll out of social prescribing across the UK was catalysed by the work of Bromley by Bow church, which set up an exemplary community centre in 1984

<sup>&</sup>lt;sup>2</sup> Ferngren, GB. 2009. Medicine and Health Care in Early Christianity. Baltimore: Johns Hopkins University Press. Ch 6. <sup>3</sup> Summers, A. 1994. The Costs and Benefits of Caring: Nursing Charities, c.1830-c.1860. In: Barry, J., Jones, C (eds). Medicine and Charity Before the Welfare State. London: Routledge. Ch 8.

<sup>&</sup>lt;sup>4</sup> Goldman, L. 2019. Founding the Welfare State: Beveridge, Tawney, and Temple. In: Goldman, L. Welfare and Social Policy in Britain Since 1870: Essays in Honour of Jose Harris. Oxford: Oxford University Press. Ch 3.



# The goal is to enable everyone to flourish

The goal of a reimagined system of care and support is to enable all humans to flourish Care can sometimes be reduced to tasks, focusing on our physical needs of eating, drinking and going to the toilet. Sometimes safety from harm overrides all other considerations. This sets the bar too low.

Christ came in order that we might have life in all its fullness or abundant life (John 10:10). There are lots of words used to describe the positive outcomes that care and support should focus on: quality of life, wellbeing, happiness. Policy documents talk about enabling people to live a meaningful life, normal life, or ordinary life.

Care and support need to focus on the whole of our lives and enable us to flourish – to live life to the full and with hope. This means participating in education, work, family life, play, community, and worship.

to support their local community. As long as there are people in need of care and support to enable them to live a full life, the church has an obligation to contribute.

#### **Our Values**

In his book 'Reimagining Britain' Archbishop Justin says that 'the way we care for others is a key marker of our values'. We took the view from the outset that our thinking and eventual recommendations should be based on an explicit set of values. Our values (set out below) draw heavily on the theology of care and the basic tenets of Christianity and have evolved in our discussions with stakeholders and with people who have lived experience of care. Some are similar to the principles espoused in policy documents and reports produced in recent years. The values we have arrived at commanded strong support from participants in our Listening and Engagement Exercise and from representatives of other faiths.

Some people suggested there were values missing from our principles. Indeed, it would be impossible to cover everything. Some of those suggestions were already covered in the proposed principles. For example, enriching, fun, creativity and happiness are part of what we mean by flourishing. The value of mutuality is about enabling participation and recognising our interdependence on one another. Other suggestions such as accessible and fully-funded are more likely to be features of a system that is based on principles of inclusivity and fairness, rather than principles in their own right. We sought to reflect the need for care and support to promote autonomy, give people choices and be person-centred in our principle of trust. We consciously chose to use different language and concepts to recognise our interdependence deriving from our shared humanity where all are valued, rather than concepts that are linked to consumerism and markets.

Some found the concept of 'loving kindness' alien. It is more than a feeling or emotion. 'Loving kindness' translates the Hebrew word 'hesed', a word linked to a story: the story

of a community and their response to a God who loved them first with patient, giving, generous and faithful love, and who are called to reflect this love in their relationships with one another. Many religious traditions have similar concepts, as with the Buddhist concept of Metta or Maitri, a mental state in which we wish for the wellbeing of others. The Biblical concept of hesed however is distinctive in its embedding in a story and the character of God – both in the Old Testament, and in its development in the New Testament. We have refined the draft principles in light of this feedback and other reflections from our work. We consider these to be fundamental to a reimagining of care and support and hope they have widespread support and relevance.

# Principles and values which should underpin a reimagined system of care and support

#### **UNIVERSAL**

Most of us will need some kind of care and support at some point in our lives. Longer lives and medical advances mean that social care has become a universal need, no longer confined to a minority of people who too often have been marginalised and invisible. Providing care and support, and paying for it, should involve a shared responsibility across society.

We are created in the image of God (Genesis 1:27), each of us unique but equal in worth before God. This amazing grace and acceptance of who we are, needs to be reflected in how we see and care for one another as a society.

#### **FAIR**

The lack of care and support when we need it is an injustice. Our collective failure to act to provide care and support is a sin.

The mission of the church is to carry on the work of Christ Jesus to 'release the oppressed' (Isaiah 61:1-2 and Luke 4:18). He identified with the marginalised in society, challenged the authorities, and turned the rules and norms of the day on their head.

This means paying heed to the voices that are seldom heard and taking action to create a system of care that is fair and provides equitable access.

#### LOVING KINDNESS

Love is at the heart of care. It is why we care. To care for and to care about others is to live out Jesus' commandment to "love one another as I have loved you" (John 13:34). This love is described in 1 Corinthians 13 and expresses itself in gentleness and kindness, reflecting the nature of God. How we care for one another needs to reflect this love. But to speak of 'love' can be a loose concept; the Christian approach to 'love' is rooted deeply in the Jewish idea of 'loving kindness', or hesed. It is about an attitude that is oriented towards the good and flourishing of the other. It is a primarily relational concept. It is not simply used as a one-off act of kindness.

Loving kindness is therefore not simply a choice but an obligation to act with justice and kindness towards others over time.

Despite very challenging circumstances, the vast majority of carers both paid and unpaid want to provide good care. Loving kindness is part of the intrinsic motivation that causes people to choose care despite low pay and under-recognition. Loving kindness is a call to wider society to be organised for the longterm flourishing of every person.

#### TRUST

Trust needs to be at the heart of the relationship between carers and cared for. We each know what matters to us and



therefore know best what we need, even if we cannot always express it. This means being given power to make our own decisions and deciding what risks we want to take as far as we are able. It also means listening to those who know us best: carers, relatives and independent advocates. We have heard too many examples where individuals had not been trusted, for example, in how they wanted to use their direct payments or in their attitude to risk.

> PROMOTING INDEPENDENCE IS RIGHTLY HELD UP AS A **POSITIVE GOAL OF CARE AND SUPPORT. YET THE BEST EXAMPLES OF CARE AND SUPPORT ARE BASED ON INTER-DEPENDENCE AND RECIPROCITY...**

#### **INCLUSION**

In Christ there are no divisions: "neither slave nor free, nor is there male and female" to this we could add "neither able-bodied or disabled, neither neurodiverse nor neurotypical, nor is there old and young" (Galatians 3:28 or Colossians 3:11). Yet many disabled and older people face discrimination, both generally and in how they experience care and can feel excluded from churches and communities, from groups or from our workplaces. Disability remains stigmatised in our society. We should challenge ableism and ageism where we see and hear it.

#### **MUTUALITY**

Promoting independence is rightly held up as a positive goal of care and support. Yet the best examples of care and support are based on inter-dependence and reciprocity – the idea that we each give and receive in different ways at different times. Regardless of our age or needs, we value relationships and belonging to community. We are social beings. The early church provides a model of living in community, of mutuality, and interdependence, where everyone has a part to play (1 Corinthians 12:12).

#### **EMPATHY**

Compassion is expressed in helping others in greater need than us. Care flows out of compassion but it can be paternalistic. Doing to others what we think they need, rather than starting with the person, and asking what matters to them.

In the true meaning of 'compassion', we get alongside others in their situation, stand or sit shoulder to shoulder, and act as allies. Doing with not for others. This requires care to be based on empathy not sympathy. It requires a deep knowledge and understanding of the other, their hopes, their aspirations, the things they enjoy and the gifts they bring.

In our view these values have profound implications for how we tackle the current challenges of social care and should be the foundation of reimagined care. But first it is important to understand the forces of change – good and bad – that lie behind those challenges.

# 2. WHERE ARE WE NOW AND HOW DID WE GET HERE?

# 2.1 Setting the context

The need for care and support has always been a feature of the human condition. In the modern era it has acquired a new importance in most countries because the numbers of us needing care are growing. Populations are increasing, more of us are living longer, and we are becoming a more diverse society. Longevity is not just about older people. Babies born with a disability and other clinical conditions are surviving to lead longer lives. Modern medicine is able to extend the lifespans of people with long term health conditions such as heart and respiratory diseases and diabetes. These advances are a great success story of our times.

But the architects of England's welfare state in the 1940s could not have imagined that eight decades later so many people of all ages but especially older people, would need so much more care, or that councils would be spending half of their care budgets on disabled people under the age of 65.

Other sweeping social and economic changes have created new challenges for care. In the 1940s the relatively small numbers of older people needing long term care would get it in the back ward of a geriatric hospital or former Victorian workhouse building, or else by their





families. These old institutions are long gone, replaced by smaller residential and nursing homes offering generally higher standards of care. But since the late 1970s, changes in public funding have encouraged the shift of most of this provision to independentlyowned organisations. Over 90% of regulated care is now provided by private and voluntary organisations. Although councils remain responsible for assessing and arranging care and support, they are dependent on others to provide it.5 Social care has become a 'market'. Until very recently not much thought has been given to the risks of this approach.

> **WE HEARD REPEATEDLY HOW CONFUSING AND COMPLEX SOCIAL CARE** IS TO UNDERSTAND AND **NAVIGATE. ALL OF THESE PROBLEMS WERE LAID BARE** BY COVID-19. THE HUMAN **TOLL HAS BEEN IMMENSE.**

The patterns and structures of family life also have changed dramatically in the last century. It can no longer be assumed that women will or should stay at home to look after children and older or disabled relatives. Expectations that women should enter the labour market as well as provide unpaid care are not equitable or sustainable. Countries whose populations are ageing very rapidly and that have traditionally relied heavily on family care, like Japan, have been the first to discover this. And in any case increasing numbers of older people have no children to call on. Yet in England the number of unpaid carers, usually family members and mostly women, outnumber the paid health and care workforce by at least two to one.6

One thing that has survived since the 1940s has been the means-test, the requirement that people should contribute to the costs of their care if they can afford to do so. Arguably this is the most striking symbol of how different social care is from the National Health Service, where most care is free at the point of use and funded through general taxation. The dramatic growth in household wealth in the last century means that many older people with care needs are caught by this, raising the oft-quoted spectre of people 'selling their homes to pay for care'. That England has one of the meanest means-tests in the world has not helped those with over £23,250 in assets face paying for all their care themselves.

Needs and costs have grown much faster than funding. Councils, faced with a 40% cut in their spending power in the last decade as a result of austerity, tightened eligibility for support and squeezed their fee rates to providers, many of whom looked to people paying their own fees to make up the difference (charging as much as 41% more than their fellow council-funded residents).7 The introduction of the national minimum wage has not been sufficient to ensure that care work is an attractive and valued job or takes account of the increasingly complex needs that people have. Even before Covid-19 came, the social care system was beset by a perfect storm of increasing demand, rising costs and workforce shortages. The system is riven by unfairness and inadequacy, with many receiving good support despite the system, not because of it.

Public awareness has not kept up with the implications of these trends. Few realise how high are the odds that they or a relative will need care, how much it will cost or that the NHS will not pick up the bill. Too often it is

what economists call a distress purchase, typically after a breakdown in family care or the need to free-up a hospital bed, when information is limited and time is short. We heard repeatedly how confusing and complex social care is to understand and navigate.

All of these problems were laid bare by Covid-19. The human toll has been immense, with the number of deaths of disabled people, and of people living in care homes, highlighting the disproportionate impact of the pandemic.8 Although additional resources from the Government helped with immediate pressures, staff shortages have worsened, with 'care deserts' in some parts of the country. There are 165,000 vacancies, a 55% increase in just one year.9 By spring 2022 over 500,000

people were waiting for social care and there has been a 43% rise in the last year of the number of home care hours that could not be delivered due to care worker shortages.<sup>10</sup> According to Directors of Adult Social Services, the situation is getting worse not better. There is not a recovery plan for social care, unlike the NHS. Indeed, social care is too often treated like a second-class service as compared with the NHS.

None of these problems are new, and the long-term challenges have been recognised by successive governments and prime ministers over the last thirty years. Whereas many other countries have introduced major reforms, in England a succession of reviews, White and Green Papers have failed to deliver meaningful

8https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/ coronaviruscovid19relateddeathsbydisabilitystatusenglandandwales/previousReleases 9https://www.skillsforcare.org.uk/news-and-events/news/new-report-from-skills-for-care-finds-filled-posts-insocial-care-are-down-for-first-time-on-record-highlighting-recruitment-challenges-for-sector 10https://www.adass.org.uk/waiting-for-care-adass-report-may-2022



<sup>5</sup> https://www.cqc.org.uk/sites/default/files/2022-07/01\_July\_2022\_HSCA\_Active\_Locations.ods

<sup>6</sup> https://www.carersuk.org/images/CarersWeek2020/CW\_2020\_Research\_Report\_WEB.pdf

<sup>&</sup>lt;sup>7</sup>Care homes market study: final report (publishing.service.gov.uk)



# Inaction as a collective sin

In looking at the history of social care reform it is clear there has been a collective failure to act, not only on the part of government, but all of us are complicit in allowing the situation to have gone unresolved for so long. Sin is a form of cognitive blindness. And so people find themselves living in systems of sin without actually knowing that they are doing so. Therefore, sin is systemic. It becomes a shared illusion that certain things are ok and just fine, which they are if you are inside and sharing in the illusion. But those on the outside looking in can see that something is seriously wrong. The prophetic task of the Commission is to reveal systems of sin and to raise people's consciousness to the illusions in which they are caught up in order that they can behave in ways that are more Godly and fairer. When a government says: "Yes of course we will deal with the problem" and then persistently does nothing, thoughtless people say: "Ah well I'm sure they will sort it out in the end," and never raise the issue again. Tough minded people don't look for easy answers and are happy to push beyond the veil, to reveal truths that are hidden and painful, the exposure of which is vital for healing.

change. The current administration has introduced a new health and social care levy, through higher national insurance, that will eventually produce more money for social care, alongside implementation of a new cap on care costs and a more generous means test. But these changes will disproportionately benefit the better off and do nothing to address unmet need. There is no workforce strategy to deal

with the escalating staff shortages that are now engulfing the sector. The measures in the Department of Health and Social Care's White Paper, 'People at the Heart of Care', move in the right direction but fall short of a bold and ambitious vision for reimagined care. In our view a clear and positive statement about the purpose of social care and the good it can do should be the starting point for real change.

# 2.2 How do people experience care and support?

We recognise that there have been many previous projects and reviews which have collected information directly on the views of people who draw on care, carers, and the public. Many of the themes in our Listening Exercise echo those of previous reports and past consultations.

As part of our Listening and Engagement Exercise, we asked people what was good about care and support and what is difficult, challenging or missing from care and support. We heard a range of views from

people who draw on care and support, unpaid carers and those who work in the care sector or organisations with a role in care and support. We published a summary of what we heard in April 2022: Archbishops' Commission on Reimagining Care - Listening and Engagement Exercise | The Church of England.

People's current experience of care and support varies. Those drawing on care and support frequently report finding it hard to access the care they need to live their lives

independently and do the things they want and need to do. Paid carers identify challenges to delivering the good quality care and support they aim for in a system of very high demand and underfunding. Unpaid carers also report facing unrelenting demands and can feel isolated, unsupported and undervalued while providing care for a family member.

Those drawing on care and unpaid carers identify challenges in navigating the statutory care and support system which in their experience is complex, time consuming, rigid and confusing. Too often respondents described having to 'fight' to get the care and support they need. Carers are exhausted, expected to do more with less support. People commonly identify problems with resources, workforce issues and leadership as getting in the way of delivering good care and support. They also consistently identify attitudes to age, disability and social care and the lack of status afforded those drawing on care and those providing it as a barrier to making improvements.

People also mentioned the positive role that communities play in supporting people, including the voluntary sector and charities, informal support networks as well as churches, gurdwaras, mosques, and temples, in addition to chaplains and other faith leaders. They specifically identified the importance of proactive local authorities, housing developments, community-led initiatives, networks for those drawing on care and caring and access to good local information.

Most people could identify a range of ways communities and churches provide support in their own community although these services are not always available and accessible to everyone. People see opportunities for these community-based services to expand with the right funding and to be more joined up.

We heard many examples of good care, but these are patchy and depend as much on where people live as on what they need. Specific examples highlighted included some councils that were working hard to meet the needs of their residents despite cuts in funding, examples of the NHS and social care working together to ensure timely and smooth discharges from hospital, supported

> **TOO OFTEN RESPONDENTS DESCRIBED HAVING TO** 'FIGHT' TO GET THE CARE AND SUPPORT THEY NEED. CARERS ARE EXHAUSTED, **EXPECTED TO DO MORE** WITH LESS SUPPORT.

housing schemes that were offering the right level of support and enabling people to remain socially connected, the use of assistive technology to enable people to live independently (as long as it is not used to replace much-needed human contact), and finally some care providers that were becoming more creative and imaginative in how they were providing care. Access to personal budgets and direct payments was particularly identified as empowering by those drawing on care and support. Good care was often about acts of individual kindness by care workers and personal assistants. It happened despite the system, not because of it.

The Listening and Engagement Exercise, which was undertaken from October 2021 - March 2022, left the Commission in no doubt that the current system of social care is broken, struggling to fulfil the needs and aspirations of people despite the best efforts of those who work in it. A fundamentally different approach, not piecemeal reform, is needed.

# 3. WHERE DO WE WANT TO GET TO? **OUR REIMAGINED VISION**

# 3.1 A values-based vision for care and support

The task of reimagining required us to lift our gaze from the challenging realities of today's situation. It was not easy sometimes to get beyond the stories and headlines of people struggling to access even the most basic of care and the critical workforce and funding shortages experienced by those providing care. To allow ourselves to imagine how things would be if we could have our prayers answered or wishes granted often felt idealistic but we have tried not to become detached from the present (see box opposite).

During the Listening and Engagement Exercise, many people told us that they want care and support to help them to achieve a



good life so they can live as independently possible. For that to happen, they want fair and affordable access to care, to live in connected communities, to have a greater involvement in their care planning, and to see a shift in public attitudes, giving greater value to those who draw on care and support and those caring. These views together with the values we developed shaped our vision of care and support in England which is that:

- · Care and support enables people to **flourish** and live life to the full
- · Access to and funding of care and support is universal and fair

- · How we care for one another reflects **loving** kindness and empathy
- Society, including churches, are **inclusive** of all people, of all ages and abilities
- · How care and support are delivered promotes **mutuality** and is based on **trust**.

We believe this should be the basis for a fundamental reshaping of care and support. Before we set out the changes needed to make it a reality, we wanted to describe how this might be experienced by someone who draws on care and support and what this might look like in practice.

# **Reimagining the future**

In the Lord's prayer Jesus makes an unusual statement: "Your will be done on earth as it is in heaven" (Matthew 24:7). The inference here is that heaven is already with us but not in all its fullness. This eschatological vision (eschatology means that it is partly here but still to come), has been central to the work of the Commission. How to be visionary and realistic at the same time? How to look to a better future and to acknowledge the many challenges and difficulties faced by people currently?

It is important that we are not bound by the parameters of our own political and social imagination, or by present systems and solutions. Instead, we are called to renew our minds, cease being limited by the things of this world, and do the things that please God ("Do not conform to the pattern of this world, but be transformed by the renewing of your mind. Then you will be able to test and approve what God's will is - his good, pleasing and perfect will" (Romans 12:2). When we do this, we are enabled to imagine, or in the terms of the Commission, to re-imagine, a future that is quite different from the present. While we are firmly located in the present with all the material complexities, troubles and blockages that come with being in the world, we are also called to notice that here, in the present, is precisely the place where heaven is and where the new Kingdom is being revealed. The vision of the Commission seeks to be heavenly and earthly at precisely the same time.



# 3.2 How does this look for someone who draws on care and support?

The goal of care and support, as the Commission has defined it in line with our values, is to enable people to flourish and live life to the full. For those of us who are disabled or have mental or physical conditions which present barriers to doing the things we want currently, our vision would mean living an 'equal life': able to do the things we want each and every day, in an environment that is accessible, free from discrimination and with the support we need to participate in education, work, family life, play, community and worship.

## 'Everybody needs the opportunity to reach their full potential.'

Access to and funding of care and support would be available to more people on a more universal basis and would no longer depend on income or wealth or where people live. Care and support would be available to people with a range of needs, from everyday support to highly specialised and complex. There would be universal support available locally in the

# **CARE WOULD BE DESIGNED** WITH PEOPLE AND WOULD **FOCUS ON KEEPING PEOPLE WELL AND ABLE TO DO AS MUCH AS POSSIBLE FOR AS** LONG AS POSSIBLE.

community and access to trusted information and advice for everyone with a care and support need. Opening up the front door as wide as possible so that people come forward at an early stage. Care would be designed with people and would focus on keeping people well and able to do as much as possible for

as long as possible. People with mild and moderate needs would also be able to access support.

# 'Care and support should be more efficient from top to bottom, bottom to top.

The care and support we would receive from both paid and unpaid family carers would reflect the values of loving kindness and empathy. Family carers together with the person with care needs would be free to choose whether they wanted to provide care and support and the level they wished to provide, enabling people to maintain loving relationships. Those who take on a bigger role would be supported to do so and could take breaks regularly. Paid carers would be valued, reflected in better pay and conditions, and they would be recruited as much based on values and attitudes as on qualifications and experience. Job roles would be redesigned with staff and people who draw on care, to create roles more akin to personal assistants. Vacancy rates would fall as more people are attracted into social care as a rewarding career.

The level and type of care and support and who provides it would be defined by the person and adapt when things change. Someone with long-term (and usually more stable) need for care and support would have the opportunity to choose whether they wish to design and arrange their own care and support or to work with a social worker or other professional to jointly design a care and support plan. It would be agreed as part of the plan how and when it will be reviewed and how people can access more urgent support should their needs change. When someone has an urgent need for care and support, they would have access to fast track identification, assessment and support and where relevant this should be provided by an integrated health and care team.

Attitudes to care and support would reflect a shift in wider attitudes to ageing and disability, from one of dependence and burden, to mutuality and gift. There would be no systematic differences in the level of care and support by age or other equality characteristics such as race, sexuality or gender. Care and support would adapt and change to meet people's needs over their lifetime as their age, level of disability and circumstances change and would be culturally appropriate, including communities that are affirming of people's identities.

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# 'We don't just want people to think about our disability. We want people to see us as an individual person.'

People would be supported to contribute to their community and opportunities to do so would be available in every community for disabled people and older people. People with higher levels of care and support needs would have more options about where to live with diverse housing that is more integrated and





embedded within communities. People would be able to build and maintain relationships with others in their communities, including with faith communities, with stronger and more frequent contact, regardless of whether people are living at home or in more specialist housing. There would be a strong sense of mutuality and interdependence in the way care and support is delivered.

# 'I really like it at church. It's the people, it's the atmosphere, it's everything. There is a feeling of belonging at church.'

People who draw on care and support would be trusted to know what is best for them and given the backing to direct their own care. While for some this would mean

taking full control of a budget, everyone would have the opportunity to set goals and define the outcomes that matter to them, and identify what would help them achieve that. Recognising that not everyone has the capacity to express what they want, there would remain an important role for close family members and friends to advocate for their loved one. People would have the right to independent advocacy, and this would be proactively offered to those who may be less able to speak for themselves due to communication difficulties or mental capacity, or who do not have a family member or next of kin who is involved in their care. Furthermore, there would be support for organisations that are led by users and disabled people who can advocate on behalf of disabled people to decision-makers and can participate in co-production of services.



# 3.3 What does reimagined care look like in action?

While our vision is clearly not a reality for everyone everywhere, we did hear about and see examples where elements of the vision are being delivered, often despite the system and in the face of challenges. During the Listening and Engagement Exercise we invited people to share examples of innovative care and support, we also held a series of roundtables in partnership with the Church Urban Fund, NCVO, and the National Care Forum which gave us insights into the work of churches, community and voluntary organisations and not-for profit providers of care and support respectively. We also engaged with Dioceses to understand more about how local parish churches are supporting older and disabled people in local communities. This gave us a rich picture of the diversity of care and support being delivered across the country and helped us to glimpse what our vision of reimagined care might look like in action. We share below a few examples from the visits that we made as Commission Members to give a taste of the insights we gained.

# **Woodside Care Village**

Visiting Woodside Care Village, a purposebuilt and designed care home for people with dementia, mobility needs, and hearing loss, was a fantastic opportunity to see the best of community support in a residential setting. The residents have everything they need on their doorsteps in the 'village'. There's a hair salon, spa, cinema, shop, and laundrette. The houses feel homely because they are. Everyone lives in a residential household, each of which has a distinctive décor and spirit. When you put the right environment around people living in institutional settings, they can thrive in community.

# Esk Valley **Camphill Community**

As a Commission, we've been thinking carefully about the purpose of care and support. Visiting Esk Valley Camphill Community, we saw a group of adults of different ages being supported to live together. The magic ingredient was shared participation. Residents live alongside each other in a community house, cooking and eating together, experiencing a sense of mutual involvement in, and ownership of, their shared space. Work is about bringing the best out of people and watching them thrive. Everyone in the community at Esk Valley has the opportunity to pursue a vocation to the best of their ability: from working on the land - tending chickens, growing vegetables - to stacking the shelves in the health shop or baking bread, everyone is equipped to share their skills and gifts.

#### **Methodist Homes Association Moor Allerton**

When we asked people what they thought a reimagined vision of care and support should be like, they often mentioned the importance of spiritual care. At MHA Moor Allerton, we saw for ourselves the difference it makes to residents when their spiritual and emotional care are treated seriously. Visiting with the Chaplain, we met residents who were able to attend church services on-site, or to have their priest come directly to them. Pastoral support lay at the heart of what we saw. When people had found things too much living in their home, MHA Moor Allerton was seen by residents as a home where they could feel safe, enjoy social activities, but also maintain their independence by living in their own flat.

#### Tonic @ Bankhouse

Society has changed enormously in recent years and as a Commission we were tasked with thinking about the various ways in which some people might find it harder than others to draw on care and support. Tonic @ Bankhouse is a ground-breaking residential setting: the UK's first LGBT+ affirming retirement community.

# **TONIC @ BANKHOUSE** IS A GROUND-BREAKING **RESIDENTIAL SETTING:** THE UK'S FIRST LGBT+ **AFFIRMING RETIREMENT COMMUNITY.**

On our visit, we heard that care and support is about understanding what people need, their background and experiences, helping people to embrace their identity and feel affirmed by those around them. This is especially important for older LGBT+ people, who are statistically more likely to be single, live alone, and may be reluctant to come out to their care staff. Care and support should enable everyone to feel safe and secure in their environment.

# Renew Wellbeing Café, **Kirkby Thore**

The church is at its best when the doors are open, inviting people to enjoy a place of sanctuary, laughter, and deep relationshipbuilding. Visiting Renew Wellbeing Café, a church-led café in Kirkby Thore, Cumbria, we saw first-hand that a simple concept a midweek coffee afternoon in the church building – can make a real difference for volunteers and guests alike. Indeed, the distinction between volunteers and guests was deliberately unclear, with everyone mucking in, enjoying refreshments, playing games, but also having a quiet place to sit and pray or reflect. Guests reported especially appreciating the continuity and consistency of the weekly sessions, which start and end with the same reflective prayer – for those who wished to take part - followed by a range of activities. Everyone is known, welcomed, and cherished.

Having set out our value-based vision and given a foretaste of what this might look like in practice we now turn to the actions that are needed to implement it. The gap between vision and reality, between policy and practice, between strategy and delivery, and between plan and implementation, is often where past reports and reviews on social care have fallen. It will be critical not only to agree a shared vision but to agree a roadmap for how to get there and to commit to taking action.

# 4. FROM VISION TO REALITY: WHAT NEEDS TO CHANGE?

Our reimagined vision for care and support rests on three fundamental sets of changes which we believe will deliver the vision of care we have set out above:

- Rethinking attitudes to care and support
- · Rebalancing roles and responsibilities
- · Redesigning the system

We set out our ideas below together with some suggested actions.

# 4.1 Rethinking attitudes to care and support

The Commission believes society will not be able to realise the vision of care and support without changing the attitudes which underpin the current system of care. This will require a generational shift in our attitudes in line with the values and principles put forward by the Commission. The ways we think about care, about those of us that draw on it and those of us that provide it needs to change in several ways.

A major reason why we do not value care and support is because of underlying social attitudes towards age, disability, and mental illness. Those of us who draw on care and support – whether this is due to frailty and old age, physical disabilities, learning disabilities, dementia, or mental illness (none of which is mutually exclusive) - are some of the most stigmatised and discriminated against people in our society. As a result, the work of providing care is also devalued and stigmatised. Without taking action to address stigmatisation or discrimination we will never achieve a system of care and support that truly values those of us who draw on it and contribute to it.

Fundamental to Christian theology, as we have set out earlier, is the teaching that all people are created in God's image and are of equal value and worth, regardless of age or ability (see box on page 29). Demonstrating this requires us to actively challenge negative attitudes towards ageing and disability wherever we encounter them, including within the Church. Action needs to be taken to tackle underlying attitudes to age and disability, including within the Church of England. In July 2022, the Church of England's decision-making body - General Synod committed to working towards the removal of barriers preventing disabled people from engaging with the Church, with members unanimously backing a motion which called for better data collection, more inclusive language during services, and more disabled people working within the Church.11 This is a good start. Further and faster progress on inclusion is needed to ensure that the mission and strategy of the Church values older and disabled people and sees them as a source of growth and gift.

<sup>&</sup>lt;sup>11</sup>Synod backs motion affirming disabled people in the life and ministry of the Church | The Church of England

Care and support that is based on the value of justice needs to go further. Whilst all older people, disabled people and people suffering from mental illness face barriers due to public attitudes, some individuals face multiple discrimination due to other protected characteristics such as race and sexuality. A recognition of the intersectional challenges facing people is crucial in order to reduce inequalities in access to care and support and to ensure that services and support are tailored and culturally appropriate. We welcome the establishment of a Commission on Covid-19, Disablism and Systemic Racism by the Voluntary Organisations Disability Group (VODG) to investigate how systemic racism in social care may have further worsened outcomes for disabled people from ethnic minority backgrounds.

As a result of this stigmatisation, people who draw on care and support are 'othered', and labelled as 'vulnerable' and 'needy'. We often see these as issues affecting other people, obscuring the truth that in different ways we all need care and support from others. Indeed, in our lives almost all of us will care for others at times and also receive care. If we are to reimagine care and support, we must shift our language (and thinking) from 'them' to 'us'. We must acknowledge the universality of care and support, reframing the issue as one that affects everybody.

Care and support is not often at the top of the political agenda or public conversation in the Britain. It has never had the same kind of groundswell of public concern and support that the National Health Service has



# Theology of disability and ageing

The term "disability" is primarily a way of marking out difference. Difference can be marked out positively, and it can be marked out negatively. Sadly, the latter is more often the case when it comes to disability. However, a theological perspective based on the idea of the image of God in all people, enables us to see and resist the negative frame that disability is often held in. Disability theology asks the question: "what does it mean to be profoundly disabled, to be beautiful and made in the image of God without having to change anything?" Disability in this view, is not a problem to be solved but a way of life to be lived well.

People do not want to be cared for, they want their gifts to be honoured, received, and recognised. We want empathy and mutuality to be the basis on which we care for and support one another. Society still thinks of disabled people with sympathy. Instead, there should be an emphasis on receiving the gifts of disabled people.

Attitudes towards ageing in our society are also often very negative - which is in part a consequence of the prevalent fear people have of dependency; dying; and death. We should also challenge the concept of decline in old age – and instead value the contribution of older people and their wisdom, experience and gifts.

enjoyed. There are encouraging examples of how other countries have shifted wider public attitudes to care. In Australia the 'Every Australian Counts' movement brought together hundreds of thousands of disabled people, their families, carers, and those who work to support them; their campaigning led to the introduction of the National Disability Insurance scheme from 2013. In the United States, the 'Caring Across Generations' movement - a broad coalition of care providers and labour unions as well as individuals themselves – has campaigned for better care at home for older and disabled Americans and led to the Biden administration proposing £400 billion of new investment in home care as part of the national infrastructure plan. There are some important success factors behind this progress: short-term fixes were rejected in favour of long-term planning; support for change was built by bringing together a wide

range of groups and organisations, including care providers and business organisations alongside people with care and support needs; and their aim was not a narrow one of just improving existing services but how to offer people better support to lead better lives, recognising the wider economic and social benefits to society as a whole.

There is a need for a visible and broad coalition across England – including people with lived experience of care, politicians of all stripes, civic institutions, and faith communities – to run a campaign that starts with values, takes a long-term perspective, and promotes a positive vision for care and support and makes the case for why change is needed. Only then will there be the paradigm shift needed to provoke change, both politically and within our communities, in the way we care about one another.

#### **Suggested actions**

- · As a society, we need to tackle ageism and discriminatory attitudes to disabled people in every context and do more to tackle the injustices caused by additional discrimination on the basis of race and sexuality.
- The Church of England to show moral leadership by ensuring its strategy and mission value disabled people and older people, making further and faster progress towards their inclusion; and
- using its position and voice to challenge discriminatory attitudes to disability and
- Build a grand coalition of organisations and secure funding to run a large-scale public campaign, including the Church of England and other faith groups, focused on achieving a positive vision of care and support and reframing care and support as something universal.

# 4.2 Rebalancing roles and responsibilities

Responsibility for providing and paying for social care is scattered across a range of individuals and organisations. In one or way or another, most of us have a role to play in providing support. Social care has become everybody's business. There is no clear agreement or public understanding of who is supposed to do what. There is no clarity about what should reasonably be expected from families, or how the costs of care are shared between individuals, families, and the state. Many believe, mistakenly, that the NHS will take care of all their care needs at no cost to themselves. This fog of confusion runs the risk that all solutions are laid at the door of the government to sort out; conversely it can become too easy for the state to dump its responsibilities on the shoulders of those of us who draw on care and support, our families and communities.

In the years after the Second World War, it was assumed that whilst government would offer social provision through the welfare state, women would stay at home and care for family members, young and old alike. This unspoken social contract, if it were

ever settled, has been made redundant by over seventy years of rapid changes in demography and the structures of family life and employment. So we need a new social covenant that sets out our mutual rights and responsibilities - "what we owe each other" as Minouche Shafik puts it. We use the term 'covenant' to describe this new understanding rather than 'contract' because giving and receiving care and support is far more than a transaction (see box opposite). It is a better description that accords with the values and principles that have driven our thinking.

#### **A National Care Covenant**

We propose that a National Care Covenant is developed, clearly and simply setting out the mutual rights and responsibilities. This Covenant would make clear the role of citizens, families, communities, and the state both in providing support and paying for it.

Developing such a covenant would require a major and sustained programme of public dialogue and engagement. We are suggesting something akin to the NHS Constitution and

# What is a covenant?

A covenant is a binding relationship between two partners which is held in place by the promise of both to work together to achieve the demands of the covenant. Covenants are different from contracts in that they not only relate to obligations and commitments. They are primarily personal, relational promises stated in oaths that bind people together in a common task. In the Bible the notion of covenant is quite flexible. It can relate to international treaties (Josh. 9:6; 1 Ki. 15:19), clan alliances (Gen. 14:13), personal agreements (Gen. 31:44), national agreements (Jer. 34:8-10), and loyalty agreements (1 Sam. 20:14-17), including marriage (Mal. 2:14)."\* Key to the idea of covenant is that it is a relationship and an obligation which is chosen. However, in order to enter into a covenant, you need to choose to be with someone and to do certain things in response to the covenant. Covenants are therefore not only legal or political agreements. They are a statement of solidarity with others that pledge to work with them towards a common goal. This is why the report has stressed throughout the need for moral and spiritual change, alongside political and economic changes that will be necessary to deal with the problems in our care system. A theology of covenant focuses on the kinds of covenantal relationships that God and human beings enter into. Caring for one another and loving one another is central to covenantal life.

\* Peter J Gentry and Stephen J Welum (2012) Kingdom Through Covenant: A Biblical-Theological Understanding of the Covenants. London: Crossway Books. pp. 130-31.

the process that was adopted to ensure that it had cross-party support and was co-produced with patients and staff. There may be a role for local authorities to begin this dialogue in a bottom-up way and strike a new relationship between public services and local people, as Wigan has done with the 'Wigan Deal'.12

We suggest that the covenant reflects the following:

- · A greater role for, and investment, in communities which enables everyone to stay well, including older people and disabled people.
- · A new deal for unpaid carers which ensures they have the practical, financial, and emotional support to be able to provide care, maintain a loving relationship and live

- a full life themselves
- · A stronger role for the state at national level in guaranteeing universal access to care and support, providing security against the costs of care, and defining entitlements and upholding rights.
- · Acceptance of our mutual responsibilities as citizens, including as taxpayers, neighbours and members of communities, and as people who draw on care and support and family members.

We set out some of our ideas about each of these in what follows.

# **Empowering communities**

Too often, the debate about care and support comes down to a false choice about where responsibility lies, between families 'stepping

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<sup>11</sup>https://www.kingsfund.org.uk/publications/wigan-deal



up' to provide more care for their loved ones, or the state providing the solution. There is a need for a more nuanced approach that recognises the role that communities already play and could play in supporting individuals and families to stay well and to remain connected when they need more support. There needs to be a rebalancing of roles so that the potential of communities in care and support is fully realised. Community is about both people and places. There are communities of identity and interest as well as of geography. Here we are mainly focused on place (i.e., geographical).

> **COMMUNITIES PLAY AN ENORMOUSLY IMPORTANT ROLE NOT ONLY IN** ADDRESSING PRACTICAL **NEEDS, BUT COMBATING LONELINESS AND SOCIAL ISOLATION AND FOSTERING PHYSICAL AND MENTAL WELL-BEING**

The role of communities, as both an important source of formal and informal care and support and the locus for people to develop meaningful relationships based on reciprocity,

needs to be recognised and built upon (see box below). Communities play an enormously important role not only in addressing practical needs, but combating loneliness and social isolation and fostering physical and mental well-being, which can delay the onset of the need for care and support. While community and voluntary organisations have an important role in providing support, they can also provide opportunities for people to take part in activities and meet people with similar interests. All aspects of the community should be welcoming to disabled people and older people. However, we must guard against communities being seen as a substitute for the support provided by the state, because there will always be disabled people or older people who require more care and support, including professional skills, than could be reasonably provided, or that they want to be provided, in the community.

Supportive and inclusive communities do not happen by accident; they need investment and nurturing.

The Commission has been impressed by many examples where communities are playing a crucial role in supporting people to lead good lives in their own homes, reducing the need

# Relationships at the heart of being human

Our concept of what it means to be a person ought to come from an understanding of God; not the other way round. A Trinitarian understanding of God in which complete mutual love and knowledge are infinitely shared, indicates that relationship lies at the very centre of God. Consequently, relationship is intrinsic to the very concept of what it means to be a person. Human beings seldom live in isolation from one another; we are bound together by ties of family, friendship and community. This is reflected in the New Testament concept that followers of Jesus are organically united in the Church, often described as the Body of Christ. We are joined to him and to one another in spiritual union. Individual, personal actions ought to be understood in this wider context; what we do affects others and this, in turn, affects us in a spiral of relational interaction.

for formal statutory services. With adequate investment and support, local communities have the potential to play an even bigger role - a universal offer of first contact support to provide early intervention, and with the ability to signpost people towards further help where necessary. We heard about examples where local authorities are adopting a community-based approach to care and support, variously called community led-support, local area coordination or asset-based community development. We would urge local authorities to commit to and fully implement these approaches. Local authorities are also using their wider responsibilities for transport, housing and leisure to ensure that these enable disabled

people and older people to get out and about.

Local authorities should redouble their efforts to work in partnership with voluntary and community organisations, including faith organisations, to coordinate and collaborate in providing a network of communitybased support for everyone, including disabled people and older people. Given limited resources in any community, there is a responsibility on all those in a place to coordinate and collaborate. We would like to see faith organisations building stronger links with local authorities, NHS and care providers and vice versa. We think that the Faith Covenant promoted by the All Party Parliamentary Group on Faith and Society





# The role of the church

When people look at the church, they should see tender heartedness; places where the deep love of God for the world is revealed and people discover the importance of relationships, community, and worship for their flourishing. The church should be a place where people can learn things about God, but also learn what it means to know God and to realise that part of that knowing relates to acts of generosity, standing shoulder to shoulder with the marginalised and the oppressed, offering kindness, gentleness, acceptance, and love. That is what the church should look like.

Many within contemporary Britain would suggest that it often looks nothing like that. However, the churches' failure (all churches not just the Church of England) sometimes to be a true reflection of the Gospel is a stimulus for change. Through the Commission and its work we want to reflect back both the strengths and shortcomings of the church and to speak words of peace, truth and love into both church and society in a way that stimulates loving Godly change and compassionate action.

is a good basis for strong and effective partnerships and would encourage more places to adopt this.

> IT IS KEY THAT CHURCHES **LOOK OUTWARD AND JOIN UP WITH WHAT IS ALREADY GOING ON. SOME** OF THIS HAS HAPPENED IN **RESPONSE TO COVID-19 BUT** THERE WOULD CERTAINLY **BE VALUE IN CONTINUING SUCH COOPERATION.**

Churches and other faith communities should be encouraged to adopt asset-based approaches – focusing on their community's assets alongside their needs - to their social action. A good starting point is to ask: what else is needed and what do people want? This approach guards against the problem of one person or small group of well-intentioned people in a church setting something up for which there is little or no demand

or which duplicates an existing activity provided by another voluntary or community organisation or another faith group. It is key that churches look outward and join up with what is already going on. Some of this has happened in response to Covid-19 but there would certainly be value in continuing such cooperation.

The Church of Scotland has funded training and support for some of its most deprived parishes to adopt an asset-based community development approach. Within the Church of England, programmes such as Places of Welcome supported by the Church Urban Fund provide examples of how to nurture community support in churches. The Church of England should consider, with partners, investing in developing further resources for and capacity in local churches to adopt an asset-based approach to engaging with disabled people and older people in their communities. In line with our principles of empathy and mutuality this is not doing to others but empowering and building up community. It is about seeing the gifts in

people and communities and nurturing these. We would like to see investment going into local communities to support community infrastructure and networks as well as small community grants for members of the community who have ideas for informal support activities. Ongoing and sustained financial support for community infrastructure could be achieved by increasing funding for prevention and community support within local authorities, similar to the Leeds Neighbourhood Network. There are also examples of where funding from other sources such as community foundations or the National Lottery Community Fund is being used to support community development. We would like to see examples like Community Chests evolving so they become joint funds from statutory, charity and philanthropic sources.

Churches can act as community hubs providing a space and place for people to connect and contribute, to get information and advice on a broad range of issues including benefits, housing, social opportunities, and support groups. In many

places especially rural communities, church buildings are an important community asset. Many churches and other places of worship are already used by the wider local community, and we would encourage churches to consider how it can best support the work of community groups whose work is aligned to the church's mission of love and care for one another.

In line with our principle of inclusion it is critical that these spaces are inclusive and accessible to everyone, to people with physical disabilities, learning disabilities, hearing or sight loss, people with mental health problems, people with autism or who are neurodiverse, those with dementia. It is vital that there is more awareness, training and support for churches and other faith communities wishing to be more inclusive and accessible. It also means ensuring they are open and welcoming to all people, regardless of who they are or what they believe. It is important that churches view everyone as having gifts to offer and opportunities to contribute and serve as far as they are able.

#### **Suggested actions**

- · All local authorities to lead the coordination of a network of community-based activities, working in partnership with faith-based organisations. These activities should include groups for the whole community as well as more targeted groups for disabled people and older people.
- · The Church of England, with partners, to develop resources for local churches to adopt an asset-based approach and to

- increase awareness of and engagement with disabled people and older people in their communities.
- · More investment in community-based approaches to care and support, and explore the creation of community funds in partnership with local government and other charitable funders to support this.



#### A new deal for carers

Communities and the state need to commit to providing a level of care and support that ensures that informal caring relationships can be entered into out of love and choice. To do this, we need to rebalance where responsibility lies, with the role of the family fundamentally altered so that unpaid carers can freely enter caring relationships out of love, not out of necessity.

At their best, voluntary caring relationships between family, friends and neighbours can be richly rewarding experiences for both the person providing care and the person drawing on it. However, as already described, the current lack of adequate support for unpaid carers can mean that these carers often find themselves stretched and strained as they try to support their loved ones. This Commission

wishes to see a new deal for unpaid carers so they are properly valued and supported in this crucial role.

Society needs to value the contribution of carers and this means recognising them as such. There are multiple opportunities which can and should be utilised to identify people as unpaid carers, such as care planning meetings or interactions with health care services. Such identification must result in meaningful support and empowerment. Carers should expect proactive advice and support. Where family members do choose to provide significant amounts of care that would otherwise fall to the state, they should be supported to do so with paid benefits and protected restorative breaks.

The level of financial support provided should

# **Theology of Sabbath**

In essence the idea of Sabbath is that we set aside a day that we dedicate to God through rest and worship. The idea of sabbath is enshrined in the ten commandments: "Remember the sabbath day, to keep it holy (Exodus 20:2–17)." Sabbath then is when we take a portion of time and dedicate it specifically to God. Sabbath focuses our attention on God and puts the things of the world into a different perspective. Of course, we all live very busy lives and taking sabbath can be difficult if not impossible for many of us. Nevertheless, it is possible to live into the principle of sabbath in our daily lives. It is clear from the research literature that people function better and are more productive and empathetic when they take breaks. Taking breaks has psychological significance, but it also impacts upon a person's overall performance in the workplace. Importantly, effective breaks do not have to be particularly long. There is evidence that 'microbreaks' can break the monotony of physically or mentally draining work. In the context of care, having breaks, even small breaks is very important if people are to avoid being burned out and trapped in the monotony and stress of caregiving. Those with a Christian orientation, might think about such breaks as sabbath moments wherein we find time, even small amounts of time, to step out of the complexity of our caring situations, focus on remembering God before stepping back into our situation with a slightly renewed perspective. At a minimum our thinking on how best to support carers should include how best to provide times of sabbath.

reflect the hours and intensity of their care. Currently Carer's Allowance is £69.70 per week if you care for someone for at least 35 hours a week. There is a need for the level of Carer's Allowance to be urgently reviewed. In the longer term, a system where direct payments can be used to pay family carers, as in Germany, and temporary provisions that were introduced during Covid-19, should be considered. When so many unpaid carers are forced to reduce their hours or even quit their jobs, we need to make it easier for carers who are working to manage to continue working. Government needs to legislate to require employers to provide Carer's Leave, including paid leave and rights to request flexibility from day one of hire.

Carers need support to have their own full and independent life. Currently support is for times of crisis, not restorative. Within Christian theology, the weekly practice of Sabbath offers a model of the importance of rest (see box opposite). Unpaid carers should be entitled to take breaks at a time, place and duration that suits them and the person they care for, with longer paid breaks for those who need them. Many churches and other organisations provide activities for people and their carers to attend. It is important where possible that carers and the person they care

for have the opportunity to spend time away from one another.

Caring can, sadly, strain relationships and change dynamics, leading to resentment or guilt on either side. By ensuring there are adequate alternatives to unpaid care available, we can protect both parties and give people the freedom to decline to either provide or receive care from their family member. Some people, due to upbringing or culture, consider it non-negotiable that they should care for their family members. It is important that the process of assessment does not assume the availability of unpaid care nor make people feel obliged to provide care and support due to the lack of funding available. Once a person's budget has been set, a further discussion can take place about who could provide the support to achieve those goals and can begin to look at the person's own strengths, assets, and support networks, including friends, family and the wider community. We heard from people who draw on care and support that they wanted, for example, their loved one to remain their husband or mother rather become their carer. This is why care provided by friends and family should remain voluntary for both the person who draws on care and support and those providing care and support.

- The opportunity for rest through the availability of different types of breaks to suit people's caring circumstances.
- · Greater recognition of unpaid carers, together with provision of proactive advice and support from voluntary and statutory agencies.
- · Increased financial support for those who take on a caring role and requirements on employers to provide more support to those who are juggling work and caring.

#### A universal entitlement

If everyone in this new covenant is to shoulder their fair share of care and support, the state will need to commit to clearer responsibilities around managing common risk. The state must take a stronger role in enabling people to pool the risks we face in our care and support needs, which will require increasing collective funding of care and support. Currently social care is the meanest of mean-tests, with most people having to pay charges even if they are receiving local authority funded care. The Government has a vital role to play, working with local authorities, to ensure there is sufficient funding and in setting the policy and legal framework through which services are provided. We suggest there should be three elements to this new universalism.

Firstly, care and support should be a universal entitlement on a par with the NHS. Everyone

regardless of wealth and income should get the care and support they need to live a good life when they need it. We recognise that achieving this will take time, but we urge all political parties to commit to this as the ultimate end goal for social care reform. One possible way that entitlement could be extended over the next decade, building on the current set of funding reforms would involve moving beyond protection from catastrophic costs, making the cap more generous so that more people of all ages benefit and, as the economy allows, gradually expand entitlements to care and support.

Secondly, the offer of care and support should be more generous. Currently for those who are eligible for publicly-funded care, only those who have the highest level of need are able to access care and support. This means that those with fewer support needs and even those with moderate needs find they do not



get any care and support. The result of this is that many people who need care and support go without or unpaid carers have to fill the gap. To achieve our vision it is important that care and support is expanded on the basis of need. We would suggest that as an immediate step the government restores the level of local authority funding for social care to at least the levels that would have been spent if funding had kept pace with inflation and changing demography over the past decade, so that more people with moderate needs receive care. We propose that early intervention and community-based support is part of a universal offer to everyone and does not differentiate between self-funders and those who receive local authority funded care and support.

Finally, there is a need for the state to define more clearly the rights and entitlements people can expect as part of a reimagined vision of care and support and ensure that these are understood and upheld by those who fund and provide care. Our proposal above for a National Care Covenant would go some way to achieving this. There are existing rights under current legislation such as the Care Act 2014 and the Equality Act, but the

FINALLY, THERE IS A NEED FOR THE STATE TO DEFINE MORE CLEARLY THE RIGHTS AND ENTITLEMENTS PEOPLE **CAN EXPECT AS PART OF** A REIMAGINED VISION OF **CARE AND SUPPORT AND ENSURE THAT THESE ARE UNDERSTOOD AND UPHELD** BY THOSE WHO FUND AND PROVIDE CARE.

issue is that these are not implemented. More robust mechanisms are needed to enable existing rights to be enforced that do not rely on individuals to bring cases. This might include strengthening and broadening the remit of the Parliamentary and Health Service Ombudsman and the Equality and Human Rights Commission. Consideration could also be given to implementing Article 19 of the United Nations Convention on the Rights of Persons with Disabilities into UK law.

- · A long-term commitment to achieve universal entitlement regardless of wealth on a par with the NHS and a road map of the steps needed to get there.
- · An immediate increase in funding to enable local authorities to meet unmet critical needs and/or wrongly met needs, some
- moderate needs and a universal offer of early intervention and community-based support.
- New and stronger mechanisms to ensure existing rights to care and support are upheld.



#### Acceptance of our mutual responsibilities as citizens

The Covenant as we have described it would be based on a mutual agreement between citizens, communities, and the state. Critical to this are citizens and the responsibilities we have to one another. There can be no rights without responsibilities. The above vision will only be possible if we play our role as taxpayers, neighbours and members of communities, and as people who draw on care and support and family members.

> **HOWEVER, BASED ON OUR VALUES OF FAIRNESS AND JUSTICE, WE WOULD WISH** TO SEE FUNDING THAT IS PROGRESSIVE, THAT TAXES BOTH WEALTH AND **INCOME, AND SHARES THE RESPONSIBILITY FAIRLY** BETWEEN INDIVIDUALS, **HOUSEHOLDS AND BUSINESSES.**

We recognise that extending entitlements so more people benefit from a universal system of care and support will require more of us to contribute to its funding. We believe that pooling the risk of disability (as we do with ill health) and providing security for disabled people and those who need care and support is part of our collective responsibilities to one another. It has not been our remit nor indeed our expertise as a Commission to propose fiscal policy options. These have been well rehearsed by others. However, based on our values of fairness and justice, we would wish to see funding that is progressive, that taxes both wealth and income, and shares the responsibility fairly between individuals, households and businesses. We would also wish to see an independent review of charges

currently made by local authorities. This review should consider the affordability of current charges and their impact on financial benefits, and set out a timetable for reducing and eventually eliminating charges, so that social care is more in line with the NHS.

During Covid-19 we saw an outpouring of help, with neighbours setting up informal groups to arrange shopping for those who were isolating and churches and voluntary organisations mobilising to collect prescriptions and keep an eye on people in their street. We see similar responses when communities are hit by flooding or other emergencies. It is clear there is a desire and willingness to help one another - to love our neighbour in the words of Jesus. In order for community support and opportunities for participation to be available consistently for disabled and older people in every community, we must firstly be aware of the needs of those around us and willing to give time and create opportunities. These informal acts of kindness are commonplace in churches and faith communities and giving up time regularly as a volunteer is often part of the 'service' expected of people of faith. Supporting and encouraging volunteering and mobilising neighbourliness is a vital role for the church and faith communities, but they must also create inclusive opportunities for disabled people and older people to contribute in a spirit of reciprocity.

Finally, when we require care and support or find ourselves, as most of us will, with a family member or friend in need of care and support, as well as exercising our rights and being clear about our entitlements, we also need to recognise our responsibilities. Not the responsibility that so many currently bear, because of a system that is heavily rationed, and which for many feels like a burden. But the responsibilities that come with trust and which enable co-production. For example, to

use budgets wisely, to share information, to engage with professionals to design and plan services, and to provide honest feedback.

- · Collective funding for care and support based on principles of fairness and equity and an independent review of social care charges made by local authorities.
- · Church and faith communities to encourage and support volunteering and
- neighbourliness in the wider community and create opportunities for participation by disabled and older people.
- · Those who draw on care and support and their carers to be enabled to engage in coproduction and care planning.





# 4.3 Redesigning the system

It is clear from all we have heard that tinkering with the existing system will not be enough. Care and support needs to be redesigned radically in order to deliver on the values-based vision we have set out.

# Simple, consistent and person-centred care planning

The driving principle of redesigned social care is to place each person at the centre of decision-making with much more freedom to shape their own care and support arrangements – this has been described as self-directed support. Care and care planning should focus on the person, their goals and what they need to live a good life. We are proposing to separate the decisions about money (assessment) and decisions about the care and support that people can access (care planning).

The approach to calculating a direct payment or budget should be simple, clear, and consistent based on broad categories of need, which would be less medicalised and bureaucratic. We propose consideration is given to the systems in use in Germany and Australia which use activities of daily living and instrumental activities of daily living or similar. For those who do not wish to manage their own direct payment, a range of alternative options should be available, including the choice to have a third-party organisation manage the budget on their behalf as already happens with individual service funds.

Care planning should be available to everyone. Fundamental changes are required to ensure that it works best for people with care and support needs. Strengths based practice should become the norm, understood not as a means of rationing care, but as a conversation that starts with 'what matters to you' and what support is needed to live the life you want.

There should be more flexibility in the way that budgets are spent too, trusting people to make good decisions. Shifting more power and control to people will involve a big change in the role of local authorities, moving to a more strategic role of looking at gaps in services and support and supporting the entry and expansion of services that people want. This must be co-produced with people who draw on care and support and disabled people's organisations and other user-led groups.

Being able to access good care should be a right, not a fight. A greater emphasis on rights and entitlements (as proposed above) will need to be accompanied by access to independent advocacy to help ensure these rights and entitlements can be exercised by those who draw on care and support. This is subject to an important caveat that such rights have meaning only in the context of the mutual responsibilities and obligations that we owe to each other. People should have the opportunity to give feedback and complain without fear of consequence and be made aware of their rights and how to enforce these. It is also important that those who are responsible for upholding and meeting those rights understand them and have the resources to meet these obligations.

# **Diverse housing options**

New housing requires investment. Building on the recommendations of the Housing Commission, the Church of England should consider how it could use its assets and investments to support the building of

more accessible housing, supported living options for adults with disabilities and other integrated community-based housing options for older people. Equity-based funding structures are bringing significant additional private - and some institutional - capital into the housing with care market. This form of social investment is property backed and has a relatively secure income stream generated from rents, and underpinned by the housing benefit system. However, bringing new social investment into expanding care provision is more complex. Typically, social enterprises, community interest companies and charities that provide services in one or several aspects of social care are small, sub-scale, and not asset backed. This makes them less likely to be able to attract social investment. However, there is scope for development in raising capital in this sector. It will require a

group of experts to work through the current challenges and find ways to make it easier to bring in patient, long-term capital.

# Harnessing assistive technologies

Technologies to assist disabled and older people with health-related mobility and communication have always been available. Though useful, these were also sometimes stigmatising, drawing attention to the user's disability and also expensive to buy and to maintain. That is transforming rapidly. More flexible and person-centred design and distribution of assistive technology should be pursued to help people stay in their own homes. Beneficial technologies can already be built in from the start, although additional costs can deter developers from innovation.





An unintended consequence of the digital revolution is how many "assistive technologies" are now mainstream and inclusive. To use a Smartphone, an iPad, a laptop, Apps, Bluetooth-or Alexa-has become the norm, for those who can afford them and are able to use them. This has brought a positive transformation in the power disabled people have to control so many ordinary aspects of their lives with ease, like everyone else. Online shopping, managing finances, obtaining repeat prescriptions, booking travel, communicating with government departments, and of course giving easy access to information, learning, and to entertainment are routinely controlled without having to leave home. Ten years ago, carers, not the individual, would have managed this.

> THE DAMAGING IMPACT OF **ISOLATION AND LONELINESS ON MENTAL AND PHYSICAL HEALTH IS WELL EVIDENCED.** ONE POSITIVE OUTCOME OF **THE COVID-19 PERIOD WAS** THAT IT SPED UP THE SOCIAL **ACCEPTABILITY AND EASE OF CONNECTING WITH OTHERS** VIRTUALLY.

The damaging impact of isolation and loneliness on mental and physical health is well evidenced. One positive outcome of the Covid-19 period was that it sped up the social acceptability and ease of connecting with others virtually. We have argued that communities can and should have greater involvement in care at the local and parish level. Every village and community of interest now seems to have its own WhatsApp group and Facebook page.

At the hi-tech end of the spectrum, sophisticated IT engineered technical

advances have already transformed opportunities in many areas of life. For example, elite paralympic sport has generated significant advances through tailor- made prosthetics and ergonomic wheelchair design. For those whose physical needs are acute there are already AI based robotics to support many of the physical tasks of daily living. However, there are still the barriers of cost, and of natural individual hesitancy to change behaviours.

We recognise that not every individual or community today can afford the available technologies that could support them. We foresee and would encourage investment that can extend the access and reach of those new technologies to become inclusive and universally accessible, as well as ensuring that technology is not used to replace the personal aspects of caring. We have been told that it is important that carers, especially those within the formal sector working in care homes and quasi medical settings, will themselves need greater levels of training to maximise the benefit of the technologies already available.

## Value based care and redesigned roles

Finally, the care system, including its providers and workforce, needs to be tethered to the values that make care and support good. At present, the currency of commissioning and provision is transactional, focused on task and time and the lowest price. Care, whether delivered at home or in a residential setting, needs to allow more time and put the emphasis on continuity of relationship, promoting wellbeing. Costs have been stripped back to the minimum (including the lowest pay) and yet despite this some providers continue to make significant profits. Rather than focusing on whether provision should be provided privately or by the state, we hope to see the not-for profit sector grow,

that is care delivery that enables relational care to be given. Providers should look to ensure they are supporting people to take as much control as they want, to contribute as well as to receive, and to support people receiving care and support to engage with the wider community.

As part of a redesigned system, paid roles within the sector need to be redesigned and pay and conditions improved. Those of us with direct payments are able to employ personal assistants, a role that is poorly understood and may benefit from renaming, but where the emphasis is on enabling the person who draws on care and support to do the things they want to. In contrast the role of care workers, whether in care homes or home care tends to emphasise doing personal tasks for the person who is not capable of doing them for themselves. We suggest that organisations like Skills for Care could engage with frontline care workers from across the sector and people who draw on care and support and their carers to co-design roles that would both better meet the needs and wishes of those who draw on care and support and

be more satisfying for those providing care and support. The emphasis needs to be more on the purpose, behaviours, and attitudes and skills than tasks. Promoting these roles would potentially attract a greater diversity of people to work in the sector and enable better retention. We would also expect to see staff recruited based on values, and culture and leadership within the sector given more focus.

A lot of responsibility and risk is currently placed on the shoulders of some of the lowest paid workers in our economy. With little or no training and few career opportunities it is little surprise that vacancy rates in the care sector continue to rise. Attitudes to caring need to change, recognising the huge skills and personal qualities required to be an effective carer. Improved pay and conditions, investment in training and opportunities to progress a career should reflect parity of value to NHS work. A clear long-term plan is required for recruiting, developing, and retaining the workforce, with a balance between qualifications, values, and behaviours.

- · Everyone to have the opportunity for self-directed support whether or not they choose to directly manage a budget, and the option for this to be managed by a thirdparty (not the local authority).
- · Assessment and budget planning should be simple and consistent.
- · Care planning services should be focused on what matters most to people.

- · Access to information and independent advocacy and the ability to give feedback and complain without fear of repercussions.
- · Development of a greater diversity of housing options together with availability of person-centred assistive technology in people's homes.
- · New workforce roles to be co-designed and pay and conditions improved so they reflect parity of value to NHS work.

# 5. HOW DO WE GET THERE? **MAKING CHANGE HAPPEN**

Some of the policy recommendations we have made in this report have already been codified in the Care Act 2014, but never implemented. Similarly, faith groups and communities have been contributing to care and support for centuries, yet still significant variability remains in the quality of care that these communities provide. While many people receive excellent, compassionate, and selfless care from family and close friends,

sadly this is not true for everyone. But what is preventing us as a nation from living out a better vision of care and support? To understand how we might ensure that the changes set out here are turned into reality we have looked to other countries internationally and elsewhere in the UK for lessons and begun to set out some of the arguments that need to be won if the radical reimagining of care and support in England is to be delivered.

# 5.1 Learning from other countries

There have been many previous reviews and inquiries set up to reform adult social care in England. We hope that by starting with values and taking a long-term perspective we have added some new insights. Perhaps more importantly than the content of any policy recommendations though is whether they are implemented.

This requires a clear understanding of why previous reforms have failed to be implemented, making a stronger and more comprehensive case for reform, and in our view mobilising the public (and politicians) to see care as something universal which affects us all.

In recent years, both Japan and Germany have been able to implement major and farreaching reforms to social care. Both countries have a generous public entitlement to long term care. In Germany, reform followed reunification when the country had been through a major upheaval. The road to reform was paved by a 'Grand Coalition' of political parties and policymakers that developed

proposals and influenced opinion-formers, including employers. In Japan, the need for care was understood as a major strategic issue affecting the whole of society and the wider economic and social impacts of inaction. Japan took a long-term approach to engaging the public. It described its new social insurance scheme as 'From Care by Family to Care by Society', appealing to deeper public concerns about how future care would be offered. We think that the pandemic creates a window of opportunity for creating radical change to social care in England. The lack of care is becoming more and more visible with direct impacts beyond the family on labour market participation and social cohesion.

It is clear that Wales, Scotland, and Northern Ireland have recognised a need to act and are at various stages of implementing farreaching reforms to social care. England is getting left behind.

In Scotland, despite progress on integration, self-directed support and carers' rights, there remained a huge implementation gap

between policy intention and implementation. While there were examples of good care there was also too much unwarranted local variation, a focus on inputs rather than outcomes, a lack of prevention with interventions only in a crisis, and an undervalued workforce. The independent Review of Adult Social Care (2020-21) chaired by Derek Feeley, recommended creating a National Care Service to put care and support on an equal footing with the NHS, ensure more consistency of standards and greater portability of care packages. It proposed ending all non-residential charges and improving the pay and conditions of care workers. The Review argued that a shift is needed in the narrative to focus on investment not burden, relationships not transactions, and prevention not crisis. It also advocated for a stronger rights-based approach to care and support. There was broad consensus and

support to implement the Review findings and the formal consultation on implementation has just finished.

> THE REVIEW ARGUED THAT A SHIFT IS NEEDED IN THE **NARRATIVE TO FOCUS ON INVESTMENT NOT BURDEN, RELATIONSHIPS NOT TRANSACTIONS, AND** PREVENTION NOT CRISIS.

In Northern Ireland John Kennedy and Des Kelly undertook a review back in 2016. John came to speak to the Commission about their report, Power to People. It had a strong focus on empowering users of services to exercise consumer sovereignty with support to drive changes in the market and ensure new services were created to better meet their





needs and wants. They firmly recognised the vital role that family carers played as the 'bedrock' of the care system. They also acknowledged the importance of resilient communities to support people to live well. Very recently the government in NI has launched a consultation on reform proposals which mirror very closely the proposals made by the review.

Finally, turning to our neighbours in Wales. As part of the co-operation agreement between Plaid Cymru and the Welsh Government, there is a commitment to creating a National Care Service that is free at the point of need. They have recently announced an Expert Group that will look at the options for this.

They are signalling a desire to increase the proportion of provision that is a public service either through local government ownership or cooperatives, and are looking at parity for health and care workers in terms of pay and conditions like Scotland. In addition, the Government has introduced the Real Living Wage for social care workers.

Reform of care and support in England is long overdue. Despite recent attempts by government to introduce changes these are insufficient, lack ambition, are too shortterm and lack widespread support. It is time for a long-term strategic approach to social care. There is much we can learn from other countries as we embark on this road.



# 5.2 Making the case for reimagined care and support

There are a number of possible ways to frame the argument about why action is needed. These are not mutually exclusive but currently there is a tendency to focus in policy debates on the efficiency argument, for example in relieving pressure on the NHS, and overlook the primary purpose of what social care should really be all about.

## **Efficiency**

We are wasting money in the NHS when people who are medically fit to be discharged remain in hospital because there is no social care available. This money should be reallocated to social care to ensure efficient use of public spending. According to Nuffield Trust this winter 1 in 10 general and acute beds every day were occupied by someone fit to leave hospital who was not discharged.<sup>13</sup> Half of these are people who have a stay longer than 21 days. Pooled budgets and integration of NHS and social care would enable more funding of intermediate care and rehabilitation so that patients can leave hospital and free up beds for other patients.

The government in their Industrial Strategy Building A Britain Fit for the Future<sup>14</sup> included healthy ageing as one of the Grand Challenges, highlighting the potential economic benefits of investing in goods and services to meet growing demand from the ageing population.

# **Economic growth**

The care sector is a large and growing sector of the economy. Demographic changes mean

that there is going to be growth in demand for care for next 30 years as the baby boomers age. There are 12 million over 65s today. In 20 years' time this is set to rise to 18 million. Investment in businesses producing products and services for care consumers would generate economic growth and enable the UK to tap into a global market.

There is a further economic argument that reflects the wide social value of care and relates to the loss of productivity due to carers dropping out of work, the same arguments could be made for the disability employment gap and the levels of economic inactivity among those over 50 both due to disability but also age discrimination in the workplace.

#### Social value

Care is part of the vital social infrastructure to enable labour market participation especially of women. Caring is one of the main reasons that workers over 50 drop out of the labour market. As a result, they are not earning, not paying taxes, find it hard to return to work, and they are at higher risk of poverty in older age. Carers UK estimates that more than half of all unpaid carers find it difficult to work.<sup>15</sup> Properly funded care and carers rights are essential to the social infrastructure of society similar to child care. We have seen the difference that access to affordable child care and parental rights made to women's participation in the labour market.

The care sector itself is a huge employer and major sector in the economy (although due to the fragmentation of providers it is not

<sup>&</sup>lt;sup>13</sup>Chart of the week: What's happening to hospital discharges? | The Nuffield Trust

<sup>14</sup>https://www.gov.uk/government/publications/industrial-strategy-building-a-britain-fit-for-the-future

<sup>15</sup>https://www.carersuk.org/images/CarersWeek2020/CW\_2020\_Research\_Report\_WEB.pdf



usually seen as such). As we have discussed, care work is one of the lowest paid jobs. Better pay would generate huge economic benefits particularly in poorer areas of the country with few employment opportunities.

# Levelling up

Creating good care and support jobs is a matter of fairness and equality. Care workers are some of the lowest paid people in the workforce, and are more likely to be women, especially from ethnic minority communities. Increasing the pay of care workers would address the gender/ ethnicity pay gap. Social care already employs 1.54m workers and improving the pay of these workers will boost the real economy. Improving the wages of care workers is key to levelling up as jobs are in every part of the country.

Both disability and age are protected characteristics under the Equality Act. There are therefore strong human rights grounds on which to improve the availability of and access to care and support.

# **Human rights**

It is a matter of justice that disabled people or at older ages should be able to exercise their rights to live life to the full. The UN Committee on the Rights of Persons with Disabilities published a damning review in 2016 on the situation in the UK. Action is needed to strengthen people's rights and the processes for enforcing and upholding these.

As a Commission we have made the argument on the basis of values and principles which derive from Christian theology. We have engaged with other faiths and believe that these values have broad resonance, although different emphasis or language might be given to these values by other religions. Whilst we recognise that economic and efficiency arguments may be needed to convince

the Treasury, we suggest that the church and other faith leaders can provide moral leadership, highlighting the social value of good care and the human as well as the financial costs when good care is not available.

#### Moral

We must act because the levels of human suffering due to a lack of care and support are unethical. This requires us to make visible the consequences for people who are left without care or with insufficient or inappropriate care by for example telling the stories of people living with disability and in old age whether in our own homes or in residential settings.

There is a risk that doing so reinforces stereotypes of need and vulnerability, so it is vital that the framing is one that recognises the universality of care and caring.

# 6. CONCLUSIONS

In exploring the many pressures on people drawing on care and support, people working in the social care sector, and people who care for a family member, it has become clear that tinkering around the edges is no longer an option. This Commission is arguing that, in order to reimagine care and support, we must uphold values that recognise the dignity, value and gift of every human being.

This requires us to take actions towards rethinking attitudes to care and support,

rebalancing roles and responsibilities, and radically redesigning the system. We believe that a National Care Covenant would make it clear that care and support is about more than contractual obligations and statutory duties, but rather a deeply profound set of relationships in which we are bound to one another. Everyone has a role to play in reimagining care and support, ensuring that we can all live the full life for which we were created.





# 7. ACKNOWLEDGEMENTS



to have had the opportunity to Chair the Archbishops' Commission on Reimagining Care over the past 12 months.

I am grateful to the Archbishop of Canterbury and the Archbishop of York for placing their trust in me to lead this work. I am hugely grateful for the amazing support of my Co-Chair, the Bishop of Carlisle, James Newcome whose wisdom and insights have been invaluable throughout, and to his wife Alison for her hospitality in Keswick, providing me with a much-needed place of sanctuary to work on the Commission.

We have not worked alone. Our fellow travellers on this journey have included: John Swinton, Anna Severwright, Clenton Farquharson, Heléna Herklots, Richard Humphries, Debby Ounsted, and Jabeer Butt. Each has brought their knowledge, personal experiences, and values to the table, sharing openly and being willing to contribute ideas. Brendan McCarthy, the Church of England's National Public Policy Adviser on Medical Ethics and Life Sciences, and Roy McCloughry, former National Disability Adviser to the Church of England, have provided advice and at times challenge to the Commission with humour and humility. We have also benefitted from the advice of a range of others who between them have decades of experience of working in and around the sector: Lyn Romeo (Chief Social Worker), Emily Holzhausen (Carers UK), Sara Livadeas (Social Care Works), Julia Unwin (formerly

Joseph Rowntree Foundation), Sian Lockwood (formerly Community Catalysts), Al Barrett (Rector of Hodge Hill Church).

We have been ably supported by a great team at Lambeth Palace: Will Fremont-Brown, Clare Williams (communications); Elizabeth Addy (Bishopthorpe), Rosemary Nuamah Williams (for the first phase) and Katie Harrison (for the second phase), Louise Dominian, and Chris Mitchell who joined the team as volunteers giving generously of their time and talents; and Ali Tozer for juggling diaries with such calm and ease. We are also grateful for the wider staff within the Church of England who have provided help and practical support behind the scenes.

When I first was approached about the Commission I was working as Chief Executive of the Centre for Ageing Better, living in North London where I had recently stepped down as churchwarden and had completed the work on the Feeley Review of Adult Social Care in Scotland. I had been waiting to see what God had in store for me next. I felt passionate about improving social care in England. At the time in February 2021, despite Covid-19 having put a spotlight on care homes, there seemed little prospect of any significant changes and provided a stark contrast with Scotland where there was commitment from all political parties to implement the Feeley Review. The opportunity to bring my professional work and personal faith together for the first time was exciting. Was this the surprise I had been waiting for? I felt called to say "yes". This was the start of bigger changes. Leaving my job, moving house, leaving the church community I had become part of for the past 10 years, and moving

back to Yorkshire to be close to my parents, and now embarking on a new adventure into politics. It has been such a blessing and I am so thankful for this time.

I want to thank all those who gave up time to speak with us. This is not a report I could have written 12 months ago. It has been formed by the many conversations I have had, among ourselves as a Commission, with people who have generously given their time to speak to us, to all those we have met with at roundtables and those who wrote to us as part of the listening exercise. I am particularly grateful to Andrew Dilnot, Derek Feeley, Julia Unwin, Sian Lockwood, Natasha Curry, Jon Glasby, and John Kennedy, who came to speak to the Commission, and to Learning Disability England, Livability, IMPACT, Disability Rights UK, Race Equality Foundation, Faith Action, Church Urban Fund, Methodist Homes Association, National Council of Voluntary Organisations, Carers UK, the National Care Forum, and the Alzheimer's Society, who organised round tables for us to meet with and hear from those directly engaged as people

who draw on care and support, their carers and those who provide support. I also want to thank the various places that welcomed us warmly for visits during the course of our work and helped to shape our thinking: Woodside Care Village, Esk Valley Camphill Community, Morden College, Methodist Homes Association Moor Allerton, Joseph Rowntree Housing Association (Hartrigg Oaks), Tonic @ Bankhouse, St Michael's Wandsworth Common, Anna Chaplaincy (Kendal), and Renew Wellbeing Café (Kirkby Thore)

I also want to acknowledge the many people who have been praying for the work of the Commission. It has been wonderful to know that the work has been guided by a higher power. I hope the work brings glory, not through the words written in this report, but the changes that will follow and the actions that each of us will take to make this vision a reality.

Dr Anna Dixon MBE August 2022



# **APPENDIX 1:** TERMS OF REFERENCE

The Commission's aims were outlined in its Terms of Reference, published in July 2021:

- · To develop a radical and inspiring longterm vision for care and support in England, underpinned by a renewed set of values and principles, drawing on Christian theology and ethics.
- · To stimulate a national debate about the nature and purpose of care and to offer practical recommendations to national and local government, policymakers, the care sector, and society as a whole, about how to deliver this vision for care.
- To address wider issues that affect the status and well-being of people in later life and adults with disabilities or disabling conditions. This will include addressing the barriers that prevent all of us from enjoying full citizenship, contributing, and participating as fully as possible to our communities and wider society.
- · To propose areas for further action by the Church of England, learning from other denominations and faith communities, on ways to support people who draw on care to live well in the community.

The Commission was launched by the Archbishops of Canterbury and York, who appointed a Chair, Dr Anna Dixon MBE, who served most recently as the Chief Executive of the Centre for Ageing Better, and a Co-Chair, the Rt Revd James Newcome, Bishop of Carlisle and the lead Bishop for Health and Social Care in the House of Lords.

Seven other Commission Members were appointed, bringing a wealth of experience, expertise, and enthusiasm to the team: Jabeer Butt OBE, Clenton Farquharson MBE, Heléna Herklots CBE, Richard Humphries, Debby Ounsted CBE, Anna Severwright and Professor John Swinton. The Commission was supported by a group of external advisers, and a staff team based at Lambeth Palace managed the work of the Secretariat.

#### How the Commission worked

The Commission divided its work into four work streams:

- 1. The theology and enduring values underpinning our understanding of care and support – led by Professor John Swinton
- 2. Future systems of care and support, shaped by those who draw on care and those who provide care and support (paid and unpaid) – led by Heléna Herklots CBE and Clenton Farguharson MBE
- 3. The role of the church, faith groups and communities in enabling people to live well in their community – led by Anna Severwright and Jabeer Butt OBE
- 4. The principles for public policy, funding, and reform necessary for implementing the vision – led by Richard Humphries and Debby Ounsted CBE

The Commission met on a monthly basis via Zoom and on five occasions for in-person meetings in Birmingham, London, and York. The Commission began its work with a series of seminars during the summer of 2021 to ensure that Commission Members had access to the wealth of material and contemporary and recent thinking on social care. Invited speakers included Sir Andrew Dilnot, marking the tenth anniversary of his landmark report into adult social care funding reform; Derek Feeley, the Chair of the Independent Review of Adult Social Care in Scotland; Dame Julia Unwin DBE, author of Kindness, emotions and human relationships: The blind spot in public policy, and the Faith in Society report for the Church Urban Fund; and Sian Lockwood OBE, who encouraged us to think radically about the role of community.

We also heard from policy experts, with Natasha Curry from the Nuffield Trust, Professor Jon Glasby from the University of Birmingham, and John Kennedy spoke about his proposals for social care reform in Northern Ireland. Throughout the Commission, we have sought to engage constructively with officials at the Department for Health and Social Care, as well as politicians. We held meetings with the Minister of State, Gillian Keegan MP, the shadow ministerial team, and a meeting with the APPG on Adult Social Care. Meetings took place with organisations, charities, and individuals across the sector.

The Commission committed to working transparently and openly, with a number of opportunities for engagement throughout the process. Having published its Terms of Reference in July 2021, the Commission published its draft values and principles, inviting responses from members of the public as well as professionals. This coincided with the launch of the Commission's Listening and Engagement Exercise, which included a number of different elements. A

survey was devised and issued, with an Easy Read version published to assist participation from as wide a range of people as possible. This encouraged respondents to outline their experiences of care and support as well as to ask them what their reimagined future of care and support would look like. The survey asked people to think big, to remove the constraints of the current system and conventional wisdom in order to share their hopes, dreams and aspirations of a care and support system in which everyone has the chance to flourish.

Alongside the survey, the Commission engaged with a number of partner organisations in order to ensure that people with lived experience, especially those who draw on care and support, were enabled to feed into the process. We are grateful to everyone who shared their time and insights with us. The Commission hosted round tables in partnership with the following organisations: Learning Disability England, Livability, IMPACT, Disability Rights UK, Race Equality Foundation, Faith Action, Carers UK, National Council of Voluntary Organisations, the National Care Forum, Church Urban Fund, and the Alzheimer's Society.

Working within the Church of England, the Commission engaged especially closely with two Dioceses - Carlisle and Southwark with visits taking place to projects in these different parts of the country, and subsequent conversations feeding into the Commission's ideas and its plan of activity post-report. The Commission Chair and Co-Chair met with the Diocesan Disability Advisers' Network, the Church of England's Committee of and among Deaf and Disabled People, in order to find out more about the work already taking place across the Church of England to offer care and support to people both within churches and the wider community.

The Commission has sought to address issues of equality and diversity in its work, with consideration about race and health disparities and outcomes, a visit to Tonic @ Bankhouse (the UK's first LGBT+ affirming retirement community), as well as important issues relating to care such as housing and accessibility. The Commission has sought to recognise that a reimagined vision for care and support requires changes to a number of other areas where older people and disabled people face barriers.

# **APPENDIX 2: COMMISSION MEMBERS**



Dr Anna Dixon MBE Co-Chair, Archbishops' Commission on Reimagining Care Former Chief Executive, Centre for Ageing Better



The Rt Revd James Newcome, Bishop of Carlisle Co-Chair, Archbishops' Commission on Reimagining Care Lead Bishop on Health and Social Care, House of Lords



Jabeer Butt OBE Chief Executive, Race Equality Foundation



Clenton Farquharson MBE Chair, Think Local Act Personal Partnership



Heléna Herklots CBE Former Chief Executive, Carers UK Past trustee of Centre for Ageing Better



**Richard Humphries** Senior Policy Adviser, Health Foundation Non-Exec Director/Deputy Chair, Wye Valley NHS Trust Visiting Professor, University of Worcester



**Debby Ounsted CBE** Director, Funding Affordable Homes Sicav Non-Exec Director, Social Housing & Charity Sectors Trustee, Gresham College



**Anna Severwright** Convenor, Social Care Future



**Professor John Swinton** BD, PhD, RMN Chair, Divinity & Religious Studies School of Divinity, History & Philosophy University of Aberdeen



For further information about the Commission please contact: reimaginingcare@lambethpalace.org.uk

