Archbishops' Commission on Reimagining Care

Shaping our vision: summary of the Listening and Engagement Exercise

April 2022

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Executive Summary

The Archbishops' Commission on Reimagining Care was set up by the Archbishops of Canterbury and York with the aim of developing a radical and inspiring vision for care and support in England, drawing on Christian theology and ethics. The Commission is committed to putting the voices and views of those with lived experience of care and support at the centre of its work and deliberations.

The Commission launched the Listening and Engagement Exercise in October 2021 and sought to reach people drawing on care and support, those who work in the sector, those who care for their relatives and friends, and the churches, voluntary organisations, and other faiths groups that support people in their local context.

This paper provides thematic analysis of the survey responses (Part A) and round tables (Part B). They are a distillation and reflection of what we have heard, privileging the voices of people who draw on care and support. The Commission's final report in the autumn of 2022 and recommendations will note the findings of the Listening and Engagement Exercise as a significant body of evidence alongside others.

We heard a range of experiences of care and support from different perspectives. Some people who draw on care and support struggle to get any support and others lack the care and support they need to live life and do things they need to and want to. Others gave examples of care and support enabling them to have fun and thrive. Those working in the sector want to be able to empower and support people but reported feeling undervalued and overstretched. While unpaid carers referred to the privilege of caring for their loved ones, they too faced unrelenting demands and often felt isolated and unsupported.

Against this context, we heard the following key messages:

- Care and support should be viewed in much broader terms than is often the case, encompassing much more than practical tasks, and should take into account emotional, social and spiritual support as well as physical care.

- Care and support should be about mutuality, enabling people to have relationships where everyone contributes and receives.

- The current system has some strengths including the quality of the care and support they draw on, and the commitment and kindness of the people supporting them. Personalisation and direct payments give people control and some local initiatives provide good care including housing and digital technology. However, the quality and availability of support can vary hugely.

- The care system also has a lot of shortcomings which have a direct impact on the quality of life for people who draw on care and support: a shortage of accessible housing, lack of continuity of care staff, lack of appropriate respite, and limited availability and flexibility of support.

- The social care system faces major challenges around the lack of resources and funding, shortages in the workforce, the enduring impact of the pandemic – which often has exacerbated existing problems – and societal attitudes towards ageing and disability. Leadership and a clear plan are also missing.

- The community can and does play a major role in care and support, with a wide range of excellent support available, but this is not always easily accessible to people who draw on care and support and varies across the country. Communities have untapped potential, and voluntary organisations and statutory services could coordinate better.

- Churches and other faith groups offer wide-ranging activities as part of their ministry, with a particular focus on relationship-building with people who draw on care and support and their families. The quality and extent of this care and support can be quite variable, and there are challenges for churches and faith groups looking to offer support based on limited resources and expertise.

- Faith based organisations are not always inclusive and could do more to use their buildings and people to be at the heart of the community, building on opportunities created by the pandemic.

People often found it more challenging to break out of the current situation and system to think about what a reimagined future could look like. The following summarises the ideas that people felt should be part a new vision:

- Care and support should be about enabling everyone to achieve a good life on their own terms, with control over their own circumstances as far as possible.

- Access to care and support should be fair and affordable, based on a sense of shared responsibility for one another, and never dependent on a person's ability to pay for services.

- Strong and mutual relationships should be at the heart of care and support, with everyone living in connected communities where they are known, valued, cared for, and contributing their gifts and talents.

- People should have far more control over the care and support services they draw on, with information more readily available about the choices on offer and the implications of the decisions they take.

- Attitudes towards care and support need to change before there is any prospect of meaningful policy reform, because older people and disabled people are too often treated in society as a problem to be dealt with rather than as people with innate value.

- The statutory, voluntary and community sectors, including faith organisations, need to coordinate and join up better to provide support that is personal and flexible to the individual.

The honest reflections and experiences that were shared of care and support have enabled the Commission to draw on a broad range of perspectives and understand both the positives and shortcomings of the current system. We have also benefitted from hearing others' ideas of what a better future might look like and feedback on our draft values and principles that should underpin reimagined care.

Our final report will set out how to make a reality of the vision and the actions needed. One common theme came through loud and clear: the task of reimagining care and support requires a bold vision rather than mere tinkering around the edges.

Background

The Archbishops' Commission on Reimagining Care was set up by the Archbishops of Canterbury and York with the aim of developing a radical and inspiring vision for care and support in England, drawing on Christian theology and ethics. The Commission started work in summer 2021 by agreeing its Terms of Reference and considering the theological basis for its work. We are committed to putting the voices and views of those with lived experience of care and support at the very centre of the Commission's work and deliberations.

About the Listening and Engagement Exercise

To ensure that the vision is shaped by those who experience care and support first hand we spent the autumn of 2021 and winter and spring of 2022 listening to and engaging with a wide range of people with an interest in the future of care and support. The Commission launched the Listening and Engagement Exercise in October 2021. We sought to reach people drawing on care and support, those who work in the sector, those who care for their relatives and friends, and the churches, voluntary organisations, and other faiths groups that support people in their local context. The process included a survey about the future of care and support; holding round table events in partnership with charities and organisations to hear from people most directly affected by the issues we are examining; and 1:1 conversations with a range of stakeholders. The pandemic has had some impact on specific visits and activities, but it has not held us back from hearing from a diversity of people with a wide range of views and perspectives, and we are extremely grateful for the time, stories and ideas that have been shared so generously with us.

The Executive Summary sets out the top line findings from the Listening and Engagement Exercise. Part A of this paper sets out a summary of key themes from the responses to the Commission's survey, drawing out quotes to illustrate and indicating any striking differences by type of respondent. Part B of this paper summarises key insights from the series of roundtables we held as part of the Listening and Engagement Exercise. The analysis and write-up were carried out by Louise Dominian and Will Fremont-Barnes overseen by Anna Dixon, Chair of the Commission.

This paper is an important input into the deliberations of the Commission, alongside and feeding into other activities, in particular our work streams on theology, future systems of care, the activities of churches, faith groups, and communities, and public policy. The Commission's final paper in the autumn of 2022 and recommendations will note the findings of the Listening and Engagement Exercise as a significant body of evidence alongside others.

The views outlined below do not necessarily reflect the views of the Archbishops of Canterbury and York, the Commission, authors of this paper, or the organisations that hosted round tables in partnership with the Commission, but simply reflect what we have heard from people with lived experience – largely people who draw on care and support, but also their carers – during this evidence-gathering process.

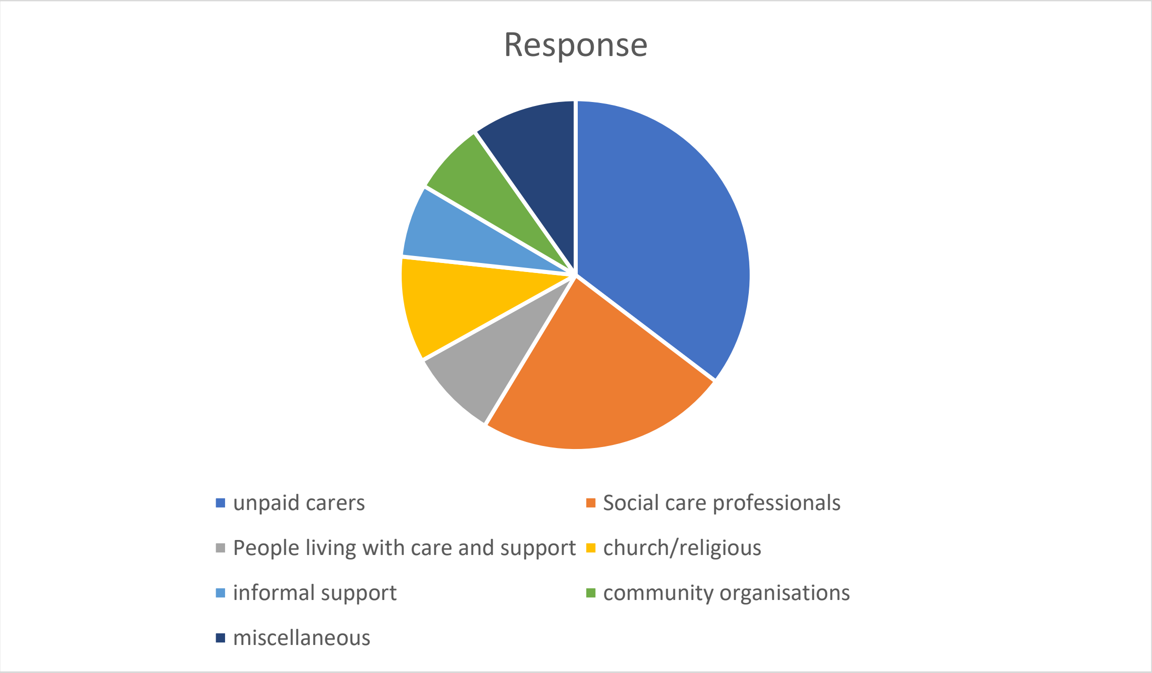
Who did we hear from?

The survey was published on Survey Monkey alongside an Easy Read version. It was advertised widely and strategically to key stakeholders, shared on social media, with reminders sent ahead of the deadline of 10th December 2021.

The Commission received 159 responses to the Listening and Engagement Exercise survey.

Figure 1 gives a breakdown of the different types of responses received. Respondents possessed a range of experiences, including paid and unpaid roles and sometimes multiple and overlapping roles in looking after relatives and friends as well as working in the sector. Health care workers and care home/domiciliary care providers were represented as well as community/charitable organisations supporting those drawing on care and unpaid carers, and national voices from the sector. The largest number of responses were received from people who act as unpaid carers for a family member or neighbour. The Commission received responses from people who draw on care and support, and has sought to privilege their ideas and voices in this paper.

Figure 1. Responses from different categories of people to Reimagining Care Commission Listening and Engagement Survey.



The survey included a range of questions as follows:

- What is your involvement with care and support?
- What do you understand by care and support?

- Describe your experience of care and support and/or care giving, whether directly or as part of the formal system of care.
- What is good about care and support currently?
- What is difficult, challenging or missing from care and support currently?
- What role does the community where you live/work play in care and support?
- What role do church and faith communities play in care and support?
- Do you have examples of good practice and innovation to share with us?
- If your wish were granted or your prayers answered, what would care and support look like in the future?
- What changes are needed to achieve your vision?
- If you could change one thing immediately, what would this be?
- What do you think of these values and principles? Is anything missing? Which are the most important?
- Is there anything else you would like to tell us?
- Is there anyone else you think we should hear from?
- Are there any other issues you think we should pay attention to?

Whilst the survey issued in October 2021, in both an Easy Read and regular format, was open to everybody – with the majority of responses received from paid and unpaid carers – we recognised that we needed to engage people directly who draw on care and support. Therefore, the Commission arranged a number of events in partnership with charities and organisations working alongside people who draw on care and support to help to shape our emerging thinking.

These sessions took place across a period of four months with the following charities and organisations:

- Learning Disability England (LDE)
- Livability
- IMPACT
- Disability Rights UK (Disabled People's Organisation – DPO)
- Faith Action/Race Equality Foundation (REF)
- Carers UK
- National Council for Voluntary Organisations
- Alzheimer's Society (Dementia Voices)

We are grateful to everyone who participated and were so generous with their time and insights.

Part A: Survey results

What is care and support?

- Care and support are understood and defined in a variety of ways, with most definitions wider than practical and personal care
- Many understand care to be a means to achieving an end goal associated with 'ways of living'
- Strong and mutual relationships are seen to be at the heart of care and support
- Recognition for the emotional, social, and spiritual dimensions of care and support
- The Care Act definition is rarely referenced and little mention of preventative care

Our respondents understand and define care and support in different ways. This varies from descriptions of activities for personal, physical, and practical care to meeting wider emotional, spiritual, and social needs (see below). Nearly all descriptions include more than practical or personal help.

Care and support can range enormously, from the intensive packages of personal care to light-touch support to help people stay on top of things. It was noted consistently that care and support should include the provision of services that people require to live as independently as possible, but should not be limited to typical tasks, such as washing and dressing, but also managing other activities that most people do for themselves, such as paying bills, answering the phone, arranging home repairs, or ordering drinks at a coffee shop. Care and support also require an emphasis on relationships, with a number of respondents noting the importance of assisting people to retain their friendships and interests, whilst feeling supported with their daily living.

There is not much variation by type of respondent in the range of descriptions, including from people drawing on care and support. One described care and support as 'an enabling service, in which a carer (paid or unpaid), assists the cared-for individual to achieve the tasks that they would not otherwise be able to achieve'. Another person described it as 'the support I need from others to get up and dressed, to enable me to live and work with as much freedom and independence as possible'.

It was noted that care and support are broad categories, and that thinking about care and support together can blur the distinction between the care offered to people where they cannot do things for themselves, whereas support can focus on encouraging people to do things for themselves as far as they are able.

Outcomes and goals

Many descriptions focused on the outcomes of care and support rather than activities per se. Care and support are most often described as help, assistance or enabling someone to achieve desired outcomes. Sometimes the definition covers outcomes for the person drawing on care and support, for example enabling people who need to access to services to live life to the full.

The outcomes for people living with care and support are most often described in terms of 'ways of living', for example: a full life, living life to the fullest, a good/quality/best life; the life people wish to live; living independently.

Personalised care is mentioned as facilitating choice. A social care professional described care and support as different to every single person, but that it should 'encompass a holistic approach. Recognising the person at the centre but also all that surrounds the person and their life and wishes'.

Respondents agreed overwhelmingly that care and support should enable people, where possible, to live independently, to be part of their own community, and to make their own decisions. This requires putting people at the centre of the plans made to assist them, and supporting people who are not able to support themselves in order to function and cope with daily living. It was noted that care and support is about 'helping someone to get the best out of their life and live how they choose by helping them to overcome any barriers they face'.

Relational care

Kindness, love, non-judgemental behaviour, and respect are identified as some of the qualities associated with care and support giving. Respondents mention both paid and unpaid care/care from families and friends. Mutuality, and giving and receiving, are mentioned by a few people. One unpaid carer described their family as providing the 'scaffolding that enables my son to fully participate in, and contribute to, a typical range of life experiences and activities'.

A researcher noted that care and support is 'ideally a relationship based on mutual love and respect that enables greater agency and/or life enhancement for the most vulnerable and flourishing for all concerned'. Another noted the importance of 'putting the person at the centre of everything – finding out what they need, want, and hope for rather than telling people what they should need or want. It should be about mutuality – seeing the person "receiving" care as one who also has something to offer'.

A national organisation described the importance of 'weaving together the formal and informal support and relationships that we can draw on to live our lives in ways that affirm our personhood and identity – the foundation of wellbeing'.

Care and support have spiritual dimensions

Although many respondents did not profess a religious faith, a number emphasised the importance of the spiritual dimensions of care and support. It was noted that caring has a healing element, and that it should enable people to live life to the full, echoing the words of Jesus in John's Gospel: 'I have come that they may have life, and have it to the full.' It was also noted that the care and support provided to people are a natural extension of the idea of progress in the Christian life. Encouraging and enabling people to grow and change is a common dimension of the Christian experience.

Where people responded without referring specifically to the spiritual dimensions of care and support, it was recognised by many that care and support is about the whole person: meeting their physical, emotional, and spiritual needs. It is recognised as a holistic process, where 'care is offered not on assumptions and task orientation but on the person's individual needs'.
A person who draws on care and support emphasised the importance of 'ensuring citizens' physical, emotional, intellectual, spiritual wellbeing is enabled wherever possible. Enabling individuals to make informed decisions about their lives'.

Wellbeing and preventative care

The definition of care and support as outlined in the Care Act is seldom mentioned by respondents directly.

There are some references to preventative care and support, but it is not common, which may reflect the fact that the majority of our respondents are unpaid carers, social care professionals, or are already drawing on care and support. A researcher noted the importance of provision taking place ahead of the need arising, emphasising the importance of 'being proactive and preventative as much as responsive and reactive'.

Experiences of care and support and/or care giving

- Those drawing on care and support mainly shared poor experiences.
- Paid carers and social workers focused on the difficulties and challenges of providing good care in a context of underfunding.
- Unpaid carers highlighted the intensity and demands they faced and the challenges of navigating the system.

People who draw on care and support

Respondents who draw on care and support mainly shared poor experiences:

- 'Participation is tokenistic. Review meetings where strangers talk about personal, private things occasionally asking me if 'That's right' without stopping for my reply. As long as I'm fed and wiped the Duty of Care has been achieved. The whole sector is underfunded and oversubscribed. Both carers and those needing care are undervalued and excluded’.

- ‘I do not yet need a lot of care, but when I have done, it has been lacking. I do not have private transport, and have had trouble accessing groceries during the pandemic. I have also had problems if I need a hospital procedure, as I have nobody to go with me or pick me up afterwards, and nobody to keep an eye on me after I'm discharged’.

- ‘I have found that it is very difficult to get care in recent years since the Disabled Living fund was cut and councils stopped supporting disabled folk in their homes. My husband has given up work in order to care for me.’

- ‘The agency that I’m currently with were great at first when I was basically bedridden. I’m now trying to follow a mobilisation schedule where I’m allowed a certain number of hours out of bed each day. This causes a problem because the doctors won’t currently allow me to get myself in and out of bed and I have to be hoisted. Trying to get the agency to understand this and make sure that my calls are scheduled so that they get the time that I need is like trying to nail a jelly to the ceiling!’

- A respondent who draws on care and support explained that ‘the process of applying for support was horrific – degrading, lengthy and invasive, with other people telling me what I could have rather than asking me what I needed’.

Paid care givers

Organisations and social care professionals offering care and support services noted that it was hard, tiring work, but could also be rewarding. They noted the difficulties they were facing in delivering care, in particular because of the way in which social care is underfunded and undervalued, and the fact that social workers are often constrained by the requirement to meet narrowly defined ‘care and support needs’. The work is described as extremely busy, demanding much of the emotional and physical energy of people who work in the sector.

Unpaid carers

Many unpaid carers referred to the privilege of caring and supporting their family members, and noted some benefits such as the opportunity to spend more time with relatives and form closer bonds. However, unpaid carers almost universally noted the difficulties they encountered, the emotional and physical demands, the unrelenting nature of their responsibilities, and the added intensity of caring for a loved one, without necessarily having the required skills or resources to perform these duties effectively. Unpaid carers often referred to the difficulties they faced in navigating the statutory system.

What is good about care and support?

- The quality and commitment of paid and unpaid carers
- The activities of churches, faith groups and communities
- Personalised care and direct payments
- Examples of good practice within the sector

Respondents were asked to name up to five things. Most respondents identified something good about care and support although there were diverse views on the good aspects of care. The majority of respondents identified less than five. Some people were unable to name one, including someone who draws on care and support, who said: 'I'm not saying there is nothing good, but I haven't experienced any strong points.'

The quality and commitment of paid care givers

People were consistently positive about the dedication of care workers.

- Residential carers are usually very kind and attentive, with considerable knowledge and awareness of what people need.

- The majority of carers are dedicated and hardworking, providing excellent care to individuals.

- One person who draws on care and support noted that 'when I get care and support, I can live my life, see my friends, study, eat well, go out'.

- There is a greater movement towards a more person-centred and inclusive approach, whilst the focus and language are becoming more humanising and empathetic.

- Nurses and carers are identified as almost always being hard-working, kind, and caring, and dedicated to their job despite being on low pay.

The activities of churches, faith groups and communities

People mentioned the positive role that communities play in supporting people, including the voluntary sector and charities, informal support networks as well as churches and chaplains.

- A vibrant voluntary sector contributes innovative local approaches to care and support, engaging volunteers in projects such as befriending.

- Charities with good information on their websites, and access to forums for support and advice. Social media has helped to build carer networks which promote knowledge of effective interventions and understandings of the legal frameworks.

- The pandemic has helped to form local support networks which have continued to operate.

- There has been a recognition in recent years that churches are trustworthy partners in health and care structures, particularly through the development of social prescribing.

- Organisations that employ chaplains in the workplace offer spiritual care in a way that makes a huge difference to people's lives.

Personalised care and direct payments

People who draw on care and support were positive about the benefits of their personalised care and direct payments:

- One person who draws on care and support noted the importance of a system that gives them control: 'We control our own personal health budget and choose our own agency. We're not victims, we control our support system. We're empowered not marginalised.'

- 'Now I have a system set up that works for me the good things are: - person budgets give me control and independence - I am in charge of my care and what I need - I am able to live a full life despite my disabilities.'

- 'The fact that it's possible to commission your own care directly'.

These benefits were recognised by others too including carers and social workers:

- 'When it works well, it can really maximise someone's independence and help them feel safe and physically and mentally well. It can reduce isolation and provide stimulation.'

- When people with learning disabilities have support to decide on their own activities and to influence services, have support to have a job, living with people of their own choosing, if not their families.

- Self-directed support was identified by others as a 'breakthrough' opportunity to focus on what people who draw on care and support want, and how they wish to live their lives.

- The shift towards more individuality in care support is leading to 'more enriched care rather than a task-focused approach'.

Good practice examples

A limited number of examples of good practice were identified, several of which focused on greater diversity of housing, as well as including:

- Funded short-term care available after hospital discharges

- Assisted technology (assuming it is not used to replace much-needed human contact)

- There is a focus on helping people to stay in their own homes and there are more options of different care and support services available.

- Some supported housing schemes offer the right level of support

- Councils working hard to meet the needs of their residents

- Care establishments becoming more creative in their care policies, recognising that simply keeping disabled people cooped up is inadequate and inhumane.

- Well-funded provision is a lifeline for many older people and their families when it exists.

Social care organisations also mentioned the role of the pandemic in raising the profile of social care work more widely.

What is difficult, challenging or missing from care and support currently?

- Lack of resources and funding
- Workforce issues
- Attitudes to age, disability and social care
- No leadership and no plan
- Impact of pandemic on care

Most people were able to identify five things that were challenging, missing or difficult with care and support. We have focused here on the top five responses.

Lack of resources and funding

These were the biggest difficult issues identified by respondents. Resources and funding were mentioned in a myriad of ways –investment in the system, unmet need, lack of time, care and support opportunities, limited range of activities and poor quality services.

- There is insufficient funding of the system, and the welfare state relies too heavily on families to carry the bulk of responsibility for care in an ageing society

- The new funding for local authorities is welcome but, along with the delayed benefits of the Health and Social Care levy, is insufficient.

- Care is largely privatised, so it does not matter what recommendations the government makes because they cannot or will not enforce the rules on private companies.

For people drawing on care and support or providing care, the lack of funding means a lack of services which has a clear impact on their quality of life.

- There is a shortage of suitable respite care.

- The cared for person has to fit into the structures of the existing system

- There is inadequate provision of culturally appropriate services for those from UKME communities.

Those funding their own/relative's care mention high cost.

- 'The costs of paid care are very, very high, if you have to pay for it yourself, and the burden is unfairly distributed, with private payers having to pay more than the local authority is charged for the same service'.

Workforce issues

Workforce issues including low pay for staff, recruitment, and retention issues (both Brexit and the pandemic were mentioned as factors in this), burnout and lack of training were widely mentioned. For people living with care and support, continuity of support was a particular worry.

- There is 'too much focus on paperwork and not enough on recruitment, retention and pay of quality staff.'

- There is a lack of supply, high vacancies rates, not helped by the pandemic and Brexit.

- 'Resources vary widely and there is often a lack of qualified carers in rural areas.

- Staff are thin on ground due to sickness and difficulty recruiting people so that means I can't go out as much'.

- There is very little continuity, carers are not nurses and do not have the knowledge or the skill to care for many of their clients. 'It is a learn as you go system.'

Attitudes to age, disability, and social care

Attitudes were seen as a challenge - the perceived low value of people living with care and support and those caring for them to society.

- There is ‘an assumption that all people who need care are less than normal people and aren't able to be in charge of their lives’.

- You are ‘treated like you don't matter’.

- There is a lack of respect and value shown to older people and disabled people, who are often made to feel as though they are a drain on resources rather than people with something to contribute and with value in and of themselves. The voices of people who draw on care and support are not heard enough.

The narrative around social care is negative and it is believed it will make people more reluctant to draw on care and support or work in the sector. This is reflected in the lack of parity with NHS for paid carers, the lack of support for careers in care and a negative narrative about care including in the media.

- Carers are often unpaid or very low paid, not making this an attractive career choice, and they are classed as unskilled in many ways and yet make a massive impact on those they care for.

- Unpaid carers also noted that much of their work is hidden: ‘people don’t know what you do or how much energy it takes to remain cheerful’; ‘it feels like everything is a fight and it’s exhausting. Sometimes it’s lonely and no-one understands just how draining and isolating it can be’.

- ‘Carers are loving a society that does not love them back.’

No leadership and no plan

The lack of national leadership with a vision and a plan setting out clear outcomes was a concern to many respondents. Policymakers were criticised for a lack of understanding about social care.

The Listening and Engagement Exercise took place during a period when the Government published several long-awaited papers on social care funding and reform. It is possible that some of the responses were received before these were published.

- ‘A plan to deal with systemic failing……Poor central government leadership, both political and civil service’.

- “It lacks a North Star - we are not working towards any measure of improving people's lives’.

- ‘Widespread lack of understanding about the type and scale of the issues’.

- ‘We do not have a policy framework which is about developing and evolving how we care for more people better: we aim for fixing the problem’.

- ‘There is an absolute lack of guidelines and overarching vision for social care.’

The current system was criticised as fragmented, characterised by poor communication and complicated processes.

- ‘It is an extremely fragmented system with major staff shortages.’

- ‘The language of systems can be intimidating, opaque and dehumanising.’
- ‘Lack of accessible and clear communication.’

Impact of the pandemic

Respondents generally had a negative view of the impact of the pandemic on carers, people drawing on care and the perception of elderly people. This is in contrast to other views that the pandemic had raised the profile of social care. Issues raised included:

- Growing perceptions of elderly people as frail and needing to be kept away from society

- Some services have closed down and pre-pandemic levels of support have not returned

- The restrictions on visiting care homes have been difficult for residents, their relatives, and care home staff

- Loneliness has been exacerbated by the pandemic, with people unable to leave their homes during lockdowns, and some people preferring to stay at home or continuing to shield rather than re-integrate in their community.

What role does the community play in care and support?

- Wide range of community support available ranging from the formal to informal support
- Mixed impact of the pandemic with an increase in volunteering but closure of some community support services
- Variable availability and quality of services in the community and transport a barrier
- Potential of communities to do more – by making use of volunteers and coordination between statutory and voluntary services

People identified a range of ways in which communities provide support. This varied from formal umbrella bodies such as Council for Voluntary Service (CVS) through voluntary groups with specific target audiences to the support from individual carers, neighbours, volunteers, and peer support.

The services on offer in the community included cafés and advice, volunteer befriending and shopping, social events, links with children, foodbanks, transport, community hub and support meetings. A number of positives were identified, particularly in the way voluntary organisations mobilised during the pandemic. The pandemic had also led to a diversity of people interacting in new and innovative ways to form networks of support.

- A number of extremely positive responses were received, with one unpaid carer describing communities as 'a lifeline of kindness, clustered in messy networks and constellations… find[ing] creative solutions to seemingly intractable problems'.

- It was noted that good work was already taking place before the pandemic. One care home worker described the activities, common across the country, of volunteers from the local community visiting to meet residents, providing company and entertainment.

- Some of these services had been adversely impacted by COVID (especially in care homes) although there were a few responses about the increase in volunteering over the pandemic.

- Some respondents noted that, whilst they know there is good community provision elsewhere, they do not always see evidence of this in their own areas. Some noted that the community services that do exist are hugely over-subscribed because there is a significant amount of need.

Relationship with statutory services

Communities have a huge role to play but are often reliant on councils having the funding to make services available for community-based groups.

Schools, churches, faith groups and local voluntary organisation provide opportunities for care and support, but this is often based on limited funding and volunteers, with very little support from statutory services.

- Communities are often better placed to provide care and support than statutory services, with more capacity for – and emphasis on – relationship-building.

- There is huge untapped potential within communities, with a particular role for communities to play in early interventions, preventing needs from escalating, but they need to be funded and supported to deliver critical services.

- A number of respondents identified the need for more funding from national and local government. The lack of coordination between local authorities and voluntary organisations was also cited by some respondents.

- Whilst much of the community provision is well organised, it can also be patchy and led by people without the necessary training and expertise, and outcomes for people are often based on those defined by statutory services.

Variability in quality and access

The quality of community support and the extent of engagement varies widely across the country.

Whilst some services are excellent, some who draw on care and support or their relatives noted that they do not have the right transport to reach these places, some housing developments can lack diversity of age/ ability, and community services may not be culturally appropriate.

- It can be hard to find community support without going out and looking for it carefully, which is an extra task to add to the list for people who draw on care and support or unpaid carers.

- Respondents in rural areas noted difficulties around lack of access transport and fewer resources, but also that it was sometimes easier to check on neighbours because of more naturally tight-knit communities.

- One person who draws on care and support noted the following from his experience of living in a residential area of bungalows, which 'houses a huge community of sick, disabled and older people. We look out for each other. There are limitations due to us all being in need of care. We cope superficially but need something more to deal with anything further. The infrastructure doesn't exist for that. It's the double edge sword of locating us all together'.

- Several respondents noted that whilst there is good community provision, the community-led day centres, activities and initiatives are not always tailored appropriately for the people living in those communities.

Potential to do more

A number of respondents noted that there was an opportunity for communities to do even more to support people, however, there were limits to how much volunteers and voluntary organisations can be expected to do.

- We have seen a huge increase in volunteering during the pandemic and communities should be supported to maintain a high level of activity.

- People are busy and do not always have the time, desire, or capacity to volunteer or look out for their neighbours.

What role do church or faith communities play in care and support?

- Church identified with a range of activities and roles
- Provision of activities beyond participation in worship and pastoral care such as memory cafes, dementia friendly activities, bereavement groups, lunch clubs. Some of these had been adversely affected by the pandemic
- Variable experience of church and faith group activities
- Challenges to churches in providing care and support
- Potential to do a lot/more in supporting those drawing on care and support and their carers and families

The survey responses demonstrated a wide range of care and support activities undertaken by churches as part of their ministry and community involvement.

Memory cafes and other dementia-friendly activities, bereavement groups, carers' support groups, lunch clubs, food banks, transportation, rough sleeper support services and hostels, drop-in centres and prayer spaces were all listed as examples of churches engaging with their community.

- It was also recognised that whilst churches can provide some support, including friendship, fellowship, and running errands, there are some tasks around care and support that members of church congregations do not have the time or expertise to undertake effectively.

- Churches could provide more carers' support groups, offering prayer and practical help.

- The Church has rightly used much of its energy to reach people through baptisms and weddings, but what about its reach to elderly people? There should be a more comprehensive framework to help churches offer bereavement support, and to help the care sector know how to connect with their local churches, working together with organisations to offer spiritual care.

It was noted generally that the provision offered by churches varies from place to place.

- Some churches offer excellent models of pastoral care in local churches, but this can be quite patchy.

- There is often good provision for people with dementia, but that others with care and support requirements are less well included in worship.

It was noted that churches and other faith communities can provide a focal point for activity, and with valuable resources such as buildings and people, they have reach into areas of the community that statutory services cannot.

- In practical terms, especially during the pandemic, it was noted that the church was 'the backbone of our social capital', and in village life acting as a 'focal point for contact and organising visits, shopping for people who are unable to fend for themselves'.

- Another noted that their village church had become the place where older people in need for company come for social inclusion and to regain their confidence and sense of wellbeing

- This involvement of faith communities in their community is often tied up in care and support, 'with a role for communities to play on a more informal level, including raising awareness of disability and the need for care amongst communities which can have limited understanding and acceptance, providing support and guidance to unpaid carers'.

Importance of spiritual care

Spiritual care was recognised by many as fundamental to a person's overall wellbeing, however important to recognise relationships can be strained by caring responsibilities.

- There were a number of testimonies provided of people being made to feel welcome, included and loved by their worshipping communities, whilst also providing helpful practical support such as signposting people on the fringes of formal care and support, enabling people who draw on care and support to lead social and worshipping activities and celebrations. People who draw on care and support appreciate the opportunity to read, lead prayers and services, and preach.

- Churches were also credited with their approach to human dignity, with one respondent noting: 'everyone can be an equal member of the community, not just a consumer of care'.

It was noted that these activities model the teaching, ministry and actions of Jesus, who 'ministered to the whole person'. There is an awareness within churches of the need for 'long term relationships, trust and connections at key stages of life's journey'.

- There are many individuals within churches who have direct experience of caring for relatives and neighbours, or of drawing on care and support themselves, and are thus able to support others well because of the insights they have gained.

- Churches could do more to recognise the fact that personal relationships – within families and within congregations – can be strained by care and support requirements.

Opportunities created by the pandemic

Many churches stepped up during the pandemic and increased their activities in the community and online, but some of this has slowed down.

Many churches have expanded their online presence as a result of the pandemic, which has allowed people to participate in worship who might otherwise not have been able to attend in person, though some activities have also stopped as a result of the pandemic and not yet resumed.

- One unpaid carer noted that their local church, which had been active during the pandemic, offering visits and increasing its online activity, was now 'more concerned with the return to normal on Sundays'. The carer added: 'I'd hoped there would be a bit more imagination about how to include people who don't normally come, or aren't physically or emotionally able to come to church'.

- Some felt that the church was not present enough during the pandemic or more generally in providing care and support.

- It was also noted by several respondents that churches have been very active, before and during the pandemic, but are not always particularly good at advertising their services or contributing to discussions with statutory services and other community organisations, when in fact the level of engagement gives churches the right to have their say in wider community efforts.

More to do to become inclusive

Respondents identified a number of challenges to ensuring that care and support services delivered by the church and faith communities were inclusive.

It was noted that some of the care and support activities arranged by churches can seem quite ad hoc, with occasional visits from clergy or dementia friendly events but without the infrastructure around them to include participants fully. Some of the barriers identified are to do with physical environment, attitudes, and unfamiliar language within churches.

- A number of respondents suggested that the Church is good at supporting people within congregations but less good at supporting those in the community who do not attend church.

- A number of respondents noted that whilst their local churches were engaged in the community and offering a wide range of activities, these were not always easily accessible by public transport, or tailored appropriately to the particular and varied requirements of people drawing on care and support.

- Many churches have ageing populations, and there is not always the capacity within such churches to provide care and support to one another.

- Churches should ask people what they support they may need and how they might like to contribute, rather than making assumptions about 'vulnerable' people.

Potential to be at the heart of community

There is potential for the Church to do more using its locations, buildings for meetings, volunteer base and authority in forming positive public attitudes.

- It was noted that the Church could be expected to involve itself more in the community; in the elderly care environment including as goal setters and help positively shape public opinion and knowledge about the sector.

- The Church had a role contributing to the richness of the community and a lot to offer in terms of coordinating and harnessing the power of the community and providing a focal point for activity. It was noted that the Church had access to resources in terms of buildings and people and had reach into areas of community that statutory services did not.

- A community organisation noted an increasing willingness and desire among members of the faith community to make a difference 'in many places they have been doing so in term of low-level community supports, but this could increase to be able to support people with more complex needs'.

There were suggestions for what the church could do differently in future. Urging the church to see care and support as integral to its mission and invest in it.

- Churches should not see care and support as a mission or project but as a way of life that affects us all.

- Openness to better collaboration between churches, care providers and communities. More church staff could be recruited to develop and work alongside/within communities.

- Every care home in the UK could be adopted by a local church with trained volunteers befriending residents.

- Church leaders should engage with government and ask for a special investment in church related caring at a local level. Churches should promote a theological and missiological understanding of caring within and among the church leaders.

Reimagining care: what would care and support look like in the future?

- Enabling everyone to achieve a good life
- A fair system that is affordable and gives people access to services they need
- More emphasis on relationships and connections in housing developments and residential settings
- Greater involvement and control for people who draw on care and support in planning
- Join things up with a greater focus on integration and shared responsibilities
- Change public attitudes so care and caring are more highly valued

Achieving a good life

Responses were frequently cast in terms of achieving a good life and other outcomes such as independence, person-centred, choice.

Some felt it was about implementing current care arrangements better and removing barriers, making a link back to how respondents had defined social care and what they thought was good/bad about it earlier in the survey.

- ‘Completely under my own control with enough funding to live a full life’.

- ‘It would look like my support not disabling me and being able to volunteer or work and commit to things because my support is reliable and flexible, and I am not exhausted from it and a lot of my support hours aren't just being spent on managing the support.

- ‘Full support to stay in my own home including housework, garden care, personal care and assistance with attending social events’.

There were a number of references to the Social Care Future vision: ‘we all want to live in the place we call home with the people and things that we love, in communities where we look out for one another, doing the things that matter to us.’

Fair and affordable access

Respondents wanted to see a system that was accessible, affordable and fairer based on a sense of shared responsibility for one another.

- Care should be available much more quickly and not dependent on a person's ability to pay.
- Easily available at the point of need with well-trained and well-paid staff who had the time to talk to people and their families in an individual way.
- 'Driven by a sense of shared responsibility for each other. Driven by a sense of betterment for all. Expressed through what we do when we look after our neighbours. Expressed through state provision as the means whereby we, the voters and taxpayers, ensure fair provision for everyone who needs it.'
- 'Sufficient funding and resources available for housing, care and support provision, access to universal services.'
- 'Substantial increase in funding for care. Local councils don't have enough budget - this should be funded to avoid any postcode lottery.'

Living in connected communities

Strong social relationships within communities are important and suggestions for how these can be supported for people living in different housing and residential settings were made.

There was a desire to see housing and living environments which promoted social interaction and that enabled people to continue to live well at home.

- Greater emphasis on relationships, with living environments designed to encourage interaction and support.
- Connected communities supporting people to live well at home.
- Downsizing, from large family homes into communities that support each other with minimal but necessary interventions from care providers.

For those living in more formal care settings the importance of staff and opportunities to engage with and in the community were highlighted.

- 'Care would be based on relationships – care teams and people receiving care matched in a way that both enjoyed and benefited from the act of caring.

- Support and funding not just for basic care needs but for individual personal assistants in care homes. Too often care homes are just meeting basic needs and failing to meet all the other needs for community and connection.

- There should be more investment in social and recreation activities, so that care home residents can feel more involved in their local and wider community

- 'If possible, I would like to stay in my own home. I am very interested in the potential of technology to make independent living easier and safer - from "smart" homes that let me regulate my environment, control access etc, even if I'm not very mobile, to wearable devices that can detect if I have fallen, or there is a problem with my vital signs, and summon emergency help.'

Greater involvement in planning

Some respondents highlighted specific improvements they would like to see in particular settings or circumstances.

These included issues around involvement in planning and self-directed support as well as support through transitions.

- Care homes should consult residents more on their care plans and wishes.

- In the transition from childhood to adulthood, there should be early planning about where people are to live as adults, or when their parents are no longer able to provide their care and support.

- The process of accessing information, finding out what is on offer and how to apply for it, and the assessment for a care plan, must be made easier for people who draw on care and support and their families.

Changing attitudes: valuing care

There was a strong desire to see a shift in public attitudes to care giving greater value to those who draw on care and support and those caring.

Respondents wanted to see the following:
- Care based on better values, not seeing people as burdens
- A recognised, valued and suitably rewarded workforce
- Greater awareness in the wider community of home carers' roles and responsibilities.
- Pride in social care like there is pride in the NHS

Respondents felt that valuing care staff would be reflected in better career opportunities and that the role of family carers needed to be recognised and valued too.

- ‘Carers would be given career opportunity. Chance to grow and progress. Also, opportunity for those academically able to progress, a social worker apprenticeship! Social workers are largely ineffective because they rarely understand the day to day lives of those they are ‘helping’. Train a carer into a social worker…???? Yes!!!!!! I’d sign up in a heartbeat.’

- Family, friends, and wider community must be seen as values essential for care rather than as an add on, as important as paid care workers.

Joining things up: integration and coordination

For many people the future would be a system in which all services worked together to support and empower disabled people and those in later life.

There was a desire to see greater integration and coordination between the statutory, voluntary and community sector and some concerns about the role of private for-profit companies in the sector.

- Blended support provided through community, voluntary, statutory sector that is flexible, strengths-based, and tailored to individuals

- Proper collaboration between statutory services, private providers, charities, the church, to ensure fully inclusive care delivery system integrated with NHS

- A number of respondents argued that care and support can only be delivered through the non-profit sector, and argued that all profits should be ploughed back into care and support, and run as community-based social enterprise communities

Few people attempted to set out a comprehensive vision of care and others noted the challenge of doing so when what is needed is something that is flexible and personal to the individual. One of the respondents who draws on care and support summed up some of the elements of a reimagined care system:

- ‘I guess it's that there isn't a one size fits all approach to care. I think that good procedures and structures need to be so flexible that individual needs are recognised throughout all the changing scenes of life. I also feel that care practitioners of every grade need to be trusted and allowed a degree of personal responsibility when caring for 'clients'. Too much is done by tick boxes these days. There needs to be some oversight of course there does, but couldn't it be in a more relaxed way’.

What needs to change and who needs to act?

- Central government needs to address lack of funding, develop a workforce plan, and publish a strategic plan and vision
- A range of organisations involved in the commissioning and delivery of health and social care need to expand new models of community-based care
- Local authorities need to commission for outcomes and on the basis of values and commissioning and support innovation and co-production
- Churches need to value and include older people and disabled people, see care and support as integral to their mission, and expand practical work on the ground
- A wide range of organisations including government, media, citizens, churches and celebs need to shift the public attitude to social care

Respondents recognised that many changes were needed to deliver the vision for care, and that the responsibility for taking action sits with many different organisations across sectors as well as individuals.

The responses are summarised in Table 1. Increase in funding was the most frequently mentioned followed by a change in attitudes about the value of social care.

Table 1. What needs to change and who needs to act?

What	**Who**	**Comments**
Funding	Central Government (Health and Social Care; Treasury)	Most frequently identified organisation and issue including reform of funding
Social care workforce plan to cover recruitment, retention, pay and training, attitudes to career in care, parity with NHS	Central Government (Health and Social Care, Treasury)	Workforce plan for future as well as current staffing shortages
Social care reform plan, new models for care, community-based models, IT and technology; simplification of system, access to care, minimum standards, national care service, integration with NHS, community and church provision	Central Government (Health and Social Care)	Responsible for long term reform of the social care landscape including clear outcomes and direction
Priority of social care, voice of those needing or living with care and their family carers	Central Government (Health and Social Care)	Listening to people living with care and support and their carers and their families.
Education – school curriculum and work with colleges on care sector; volunteering; value of older people	Central Government (other departments)	Range of other departments to support social care outcomes

Housing and Planning – future proof housing and communities for ageing Housing and Transport – provision of accessible housing and transport		
Funding and commissioning Ensure funding reaches front line More outcome and community based/values-based commissioning	Local authorities	Using current commissioning and funding to meet needs working with communities and those living with care and support.
Innovation – invest in technology that frees up time for social interaction More co-creation in meeting needs	Local authorities	
Emphasis on shared human values in social care and of people living with care and support Renewal of teaching and practice emphasising shared responsibility Educate the public about social care Local churches prioritise care homes Mission strategy for older people	Church of England/other Christian denominations	Range of views on how churches can make social care more visible and emphasise the value of those living with social care and support and their carers
Change attitudes about the value of social care Change the narrative in the media Change mindsets on ageism, people living with care and support; value of people Change attitudes to paid/unpaid care Help public/media understand social care Engage celebs, young royals to help change image	The public, The media/social media Volunteers Society Everyone	Range of other agents (as well as government and churches) to help change how social care is perceived, its narrative.

Feedback on the Commission's draft values and principles

- The majority of respondents were positive about the draft values and principles and thought they were all important.
- Some respondents challenged the values and had other thoughts about how they were used
- There was a range of ideas about what else might be included in the draft values and principles

The Commission published a set of draft values and principles alongside the launch of the Listening and Engagement Exercise. We invited feedback on the draft values and principles which were:

- Flourishing
- Loving kindness
- Empathy
- Trust and mutuality
- Universal and inclusive
- Fairness and justice

A fuller description of the meaning and thinking behind these can be found here.

Support for the values and principles

The feedback to the draft values and principles was generally positive. A number of respondents noted that they could not improve on the values, that it reflected a commitment to social justice, and that no one value could be prioritised because they were all important and came as a helpful package. Indeed, several noted that everything else needed to transform care and support flowed from a commitment to a universal and inclusive approach; that the social care system needed to be underpinned by trust; and that empathy 'must extend further into a real understanding of a person that can lead to responding helpfully and supportively, beyond just seeing their perspective'.

Challenges to the values and principles

There were challenges to the values and principles. One respondent noted that 'where there is a theology of exclusivity (only some will be saved), we have a God who is not universal or inclusive'. It was also noted by several respondents that the values and principles may not reflect a distinctively Christian approach to care and support, with the point raised that faith in God helps people in a way no amount of practical support can in providing solace and refuge. It was also noted that there is a humanist argument from natural justice for the inclusion of disabled people, and the conclusions ought to be rooted more clearly in teaching from the Bible.

The values were described by one respondent as 'condescending', with the criticism that they felt as though 'written by people outside the daily slog of care and advocacy'.

Whilst the values and principles commit to enabling people to be independent as far as possible, one unpaid carer felt that they did not recognise the challenges faced by unpaid carers who simply are not able to help their relatives make informed decisions: 'I encounter some difficulty in allowing my husband to make his own decisions and direct his own care and his memory and executive functions decline, and I increasingly have to take over some jobs that he used to do easily… the values all sound very nice and loving, but in reality the situations dealt with by carers and patients may be extremely tough, and somehow this isn't acknowledged'.

There is also concern raised that the prominence of mutuality takes away some of the responsibility from the Government to fund and oversee the social care system adequately, and can lead to the expectation that unpaid carers will meet needs that would be more appropriately met by paid professionals. One unpaid carer noted that 'we must listen and not take away the power of decision unless absolutely necessary and for their own safety', but noted that it would be helpful to have more guidance about how to make judgements about this.

Flourishing was the least well understood of the values and principles, and was described by multiple respondents as vague, as well as an end goal rather than a value in and of itself. It was emphasised that the values and principles must not be about disabled people and older people as 'other', but about all of us.

Many of the values and principles appear in care home brochures, and may be difficult to achieve unless social care is 'well-resourced and accessible'. Indeed, many if not all of these values are agreed upon from the perspective of people in the care system, but are deemed by some to be missing from other important stakeholders with the ability to influence and change the system.

Most often, it was noted that actions are more important than words, and that it would be necessary not simply to promote aspirational values but to have the means and commitment to put them into practice. A number of respondents noted that, irrespective of their intentions and aspirations, national and local government are limited by what they can afford

What is missing?

Respondents identified a range of missing elements, many of which had appeared previously in their response to what was good about social care or what their vision of social care would look like. Some, for example mention resourcing and unmet need and speak to the current crisis being experienced in social care, whereas others highlight voice, dignity, value, respect for human rights and pick up the theme of current attitudes to social care. Others mention values such as choice and independence, relationships, participation, subsidiarity, dignity, enriching, fun and creativity, happiness, person-centred care and focus on the outcomes from social care. Hope and Love were flagged as essential qualities for human living.

In the words of respondents who draw on care and support:

- 'Great words. Should include fully funded'.

- 'Agree with these values and principles, but what about choice and autonomy? A lot of this is to do with how kind people must be to others. But need to make sure rights of care-recipients are also acknowledged'. I like the idea of solidarity - between care workers and care recipients. Also, that care differs over lifetime, as people receive and give care. A better value than charity.

- 'I think these are all really important, I think I would add interdependence to mutuality to highlight how no one is independent. I would add Accessible to Universal and Inclusive, because it is one practical way to do this'.

- 'These principles are great, they reflect the biblical ideal, what we all aspire to. But disabled and elderly people need a voice, we need to be heard'.

Last words

Respondents were offered a final opportunity to tell the Commission their thoughts.

These often picked up themes already touched upon in the previous questions: lack of funding; crisis in workforce; unmet needs; need to change the narrative around the value of all involved in social care; voice of those living with care and support, measurement of key outcomes, housing.

There were some exhortations for the Commission

- 'Be inspiring Be a little kinder than you have to be.'

- 'Please be strong with the things you think are right and press the government to deliver real reform and not just tinker round the edges.'

- 'This is a big topic and the needs of groups (old, people with learning disabilities, people with mental illness in both acute and chronic care situations) are very different. Keep the intrinsic worth of people at the centre regardless of conditions and needs, this is fundamental to engaging and supporting others.'

- I would be interested to know what impact you hope to have with this, so that it is more than just an exercise...'

And some kind words of thanks and hope for our work:

- 'I love that you have developed values and principles let's get social workers back into communities to work alongside people and get upstream of difficulties before they happen' (P63 - social care professional).

- This is such a fresh way of thinking about care.

Part B: Summary of roundtables

Care and support today

The quality of care and support

'Everybody needs the opportunity to reach their full potential.'
'You're not giving up your own self, you're just asking for someone to assist you so that you can be more like yourself.'

Numerous examples were shared of care and support that is life-giving and enriches people's day-to-day lives. When support is appropriately tailored to the individual, taking into account their personality, needs, and preferences, people build and maintain good relationships with the people around them. Care and support enable people to have fun with their friends, family, support workers, and to thrive in their context. The increased availability of technology in care homes was cited as an important development by a number of participants. As people have become more digitally connected, it has become easier to keep in touch with friends and family whilst living in residential settings.

In all of the discussions that have taken place, people who draw on care and support emphasised the importance of their relationships, which are often enabled and strengthened by the quality of support received from workers. Care and support were cited as important for emotional wellbeing as well as physical health. These relationships matter both between individuals as well as at a community level. In the session with Livability, residents shared their involvement in litter picking, expressing their joy at working in partnership with others and their sense of pride about contributing to their community. Another participant noted that when their relative, who also draws on care and support, moved into a care home it had given them a new lease of life and given them the confidence to volunteer as a befriender at the local hospital.

Many people who draw on care and support paid tribute to the quality of the care and support they receive. In the session with LDE, it was noted that respite support, when delivered well, can make a big difference, and ought to be more widely available. Examples were shared about social activities on offer for people, and of a proactive county council ensuring that the voices of disabled people are heard on important consultations on traffic schemes and cycle lanes. At the Livability session, residents emphasised the importance of carers supporting people with their relationships as well as with their everyday tasks such as cooking, finances, and employment. Support staff can be extremely supportive and kind, often going above and beyond what they are required to do, offering excellent emotional and practical support. A participant from Livability noted that carers need to have very specific skills and personality types to offer the individualised support required. There was a strong degree of agreement in the Commission's round table with DPO that the individual must be in the driving seat of their own care and support, with the money available to shape their own arrangements. Whilst it can be tempting to look at different models and approaches to care, many of the ways of improving the system begin with implementing measures and duties outlined in the Care Act (2014).

A common theme across the sessions was that the quality of care and support can vary hugely. A participant from DPO noted that, fundamentally, the role of social care is to enable people to access the things they need, whether it is a wheelchair to help with mobility or a listening ear from a community befriender. Whilst there are often decent services available to people who draw on care and support, there is still confusion about eligibility needs in social care (for example, the fact that carers have legal parity of esteem through the Care Act is not well understood). A participant from LDE noted the importance of making sure that care and support is not about 'making do', but about making services really good. A participant from the DPO cited a scene from Ed Balls' recent BBC documentary about working in the care sector when he asked an elderly lady how warm she would like the water when receiving a face wash. This care and attention encapsulate the respect and dignity with which any support should be administered. This requires support workers being proactive and attuned to the needs of the person with whom they work.

A participant who lives in residential care noted that whilst their staff were always attentive, the uncertainty about who would be caring for them on any particular day could be quite disruptive and unsettling. Greater continuity of staff would enable people drawing on care and support to feel more confident about the support they are receiving. A participant shared that when they went into respite care their form had been filled out incorrectly, so what they needed and were able to do was not properly reflected in the care they received. Another participant shared details of their transition from care as a child to an adult, describing the big change in what can be accessed over the age of 18 and the chaotic way in which this was handled.

The role of housing

'Let's build houses that work for people.'

"There's a lot of talk about how digital will increase choice; it's difficult to see, if you physically need help getting in and out of the shower, how there'll ever be a digital solution that's going to help us.

The lack of good-quality, affordable housing was identified as an issue particularly affecting people who draw on care and support. A participant from Livability noted that there are not enough affordable homes for young disabled people. In the session with the DPO, it was noted that the amount of accessible new build homes seems very limited, and that houses should be built in such a way that can be easily adapted throughout a person's life. This will enable people to remain in their homes, living in their communities, for much longer, integrating disabled people in society and helping them to join in with everything like everyone else does. Even if your house is accessible, the chances are that your friends will not live in accessible housing. It was argued that assessment for housing need should be included by law in the social care assessment process, and that there should be policy changes around new-build housing and the need for accessible homes.

Where residential services have been closed, friendship groups are often disrupted. There needs to be a much greater understanding of how people's homes enable them to do the best that they can independently.

Workforce and funding

'Without our support workers, we won't be able to achieve the things we want to achieve.'
'We should all have the right to equal access.'
'Care and support should be more efficient from top to bottom, bottom to top.'

Although the sessions were primarily about people's personal experiences of drawing on care and support and what they would like to see in future, a number of policy issues were raised, including pay and conditions for the workforce and funding for the system. The consensus across these sessions was that care workers ought to be better paid and appreciated, especially in view of their efforts during the pandemic. However, the challenges caused by staff shortages across the sector was noted as a particular challenge for people in residential settings. Participants in the session with Livability highlighted the significant issues around funding, which does not always enable people to receive the personalised care and support they require. It was also noted that there is a particular need for more support in the evening and more one-to-one care. There is a huge issue about recruitment of staff, with care rarely seen as an attractive proposition for people starting out in the working world.

It was noted in the session with IMPACT that people who draw on care and support who employ a personal assistant need to be given the financial support to pay them the living wage. Too often, personal assistants are not being paid well enough, which does not recognise their contribution, nor attract and retain people with the right skills in the sector. Indeed, the DPO session focused on the fact that there is a shortage of personal assistants, with little being done to promote these roles to the extent that people starting out in employment are often unaware that this is a viable career option. There was discussion at the Faith Action/REF session about personal assistant micro hubs in Essex to give personal assistants greater flexibility about when and how they work, whilst also ensuring there is a supply for people who draw on care and support. Whilst not everyone working in the care sector is labelled a personal assistant, everyone who supports people (in a home or domiciliary care) should adopt an attitude of personal care. It was noted that some people lost their social package when the pandemic hit because they did not want people coming into their homes because they were clinically vulnerable, and not only was there little increased support available but they lost their care packages and, in some cases, had to register all over again for new support.

Unpaid carers

The Commission held a session with Carers UK, which brought together a group of carers who provide, or have provided, unpaid carer to a family member, with a particular focus on their experience of receiving support from their community. Many carers noted that they would not consider themselves a carer but, first and foremost, a loved one of the person they are caring for, and that it would not occur to them to do anything other than support their relative.

It was noted repeatedly that being a carer for a loved one, whilst necessary and hugely rewarding, can be an extremely lonely job, which is made more difficult by feelings of guilt often associated with feeling like they do not have the time or skills required to provide the care their relative requires. Carers noted that locality makes a significant difference, with a friendly local community making life much easier for carers. Initially, when care needs arise, practical issues are usually the main concern for unpaid carers, with a particular concern raised about where to go to find out what support is available to them. Online resources can help to raise awareness of what support is available, but this is not always helpful for everyone and there is no substitute for being pointed in the right direction at the local level.

It was also noted that there should be more constructive dialogue between and within faith communities, with better sharing of good ideas for helping people according to their needs and preferences. An individual's identity as defined by their faith can be very important to their sense of self-worth, whatever their physical and mental health may bring. An example was given of an elderly person who has a personal budget still insisting on attending church gatherings and helping to serve lunch, not seeing themselves as disabled but as someone who is still contributing to their community.

There are challenges for younger generations of British-born carers whose parents were migrants, where family values include the assumption that you have a duty to care for your elders, as well as to marry and have children, when this is not always financially viable, personally desirable, or in keeping with the predominant culture of Britain in 2022 which is about having a successful education, career, social life, and complete independence and freedom to do what you want. One participant, who grew up in a different culture but has lived in the UK for most of their life, noted that their first language did not have a direct translation for the word 'carer', and there is an ingrained assumption that their duty is to look after the elderly. That is particularly true for women, who in different cultures are often told that, if married, their duty is to look after their in-laws as well as their own parents when necessary. In different cultural understandings of care and support, many people grow up very accustomed both to the concept and prospect of looking after family members as they get older or develop more complex needs, but knowing this in theory still does not prepare you for the reality of doing so in practice.

A participant at the IMPACT session, who is cared for by a relative, noted that their relative should receive more support and recognition for the fact that they never clock off work. Their relative receives the equivalent of 17p per hour when they claim Carer's Allowance, which is not acceptable as a sum for this kind of support.

Where do faith communities fit in?

'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. I go for the teas and coffees and have lunch there.'

A participant who draws on care and support shared that their local church has encouraged them to participate in the worshipping life of the community in a number of ways. The church emails the Bible reading to them in advance so that they can learn it, and there is someone available to help on the day in case they do not feel well enough to deliver the reading struggle to remember the words. The church also records the words to services in advance on a CD. It was noted that in church congregations there are often a handful of people who make a particular effort to get to know people who require support to participate in church services and activities, and so it is important to involve different people so that the support does not depend on the availability and willingness of a small group. Church communities should consider it their collective responsibility to look out for people who might need additional support to participate and view this as part of their ministry.

A number of unpaid carers reflected on how their worshipping community had supported them and their relative. One described how their child with Down's Syndrome was invited regularly by his Catholic church to ring the bell during Mass, which for them is the highest realm of their religious experience. The church community also believe in helping the family by taking their relative on holiday, on days out, and arranging activities that they will enjoy. The rhythms and familiarity of liturgy was identified as extremely helpful for people with dementia, enabling people to remember words that have been important to them over the years, and also brings comfort to their loved ones.

Another participant noted that when their relative developed dementia, they found that people in the community did not know how to relate to them anymore. This faith community, which was very involved in all sorts of outreach and support for people in need, was not particularly involved or with – or able to respond to – people who were moving to the margins because of physical frailty. A number of carers noted that it would be helpful if churches in small towns, where there are disabled people dispersed across different congregations, joined together more often for services and activities. People with learning disabilities are often included in activities with children, and there is often no facility for them to be with people their own age within church congregations.

The REF/Faith Action session acknowledged that faith communities have often neglected to reach other parts of their community. In particular, members of the LGBT community have raised concerns about how they have been treated by faith communities. If faith organisations want to take public money, they have a duty to support people in a non-discriminatory way. It was also noted that whilst churches are very good at prevention, when it comes to more specialised support, such as domiciliary provision, there are concerns about church communities having to be measured against targets and KPIs, effectively being asked to perform the duties of statutory services. There are threats as well as opportunities for churches seeking to become more involved in care and support.

Reimagining care and support

'I just love the idea of reimagining. It's exactly what society needs.'
'It's difficult for disabled people to talk about vision when lives are being put under such strain and pressure now, with fears that care will be taken away.'

The purpose of these round tables, in line with the Commission's aims, is not to dwell too much on the current system but to consider what a reimagined understanding of care and support would look like. The Commission heard a range of ideas and perspectives about what people who draw on care and support want to see in the future.

More opportunities to participate

'I want the chance to let my hair down.'

The sessions with LDE and Livability led to wide-ranging discussions about the need for care and support to enable people to access more opportunities. This includes gaining skills and work experience to access paid work for good pay, and for these to be open to people of all ages rather than just young people of working age. When people have wanted to work, they have often found formal or informal barriers in their way. Opportunities should not be limited solely to employment and volunteering, with a particular emphasis in the discussions on enabling people to enjoy more leisure activities, such as going on holiday, taking responsibility for new challenges, and enabling them to exercise and be more physically active. One participant noted that care and support should be the springboard to build people up. However, inequalities around access to opportunities featured heavily in these discussions. It was noted that there are lots of activities people who draw on care and support can participate in if they have the financial means to do so, but that choices are much more limited for people who have less money. One participant suggested that the Government should make funds available for people who draw on care and support to take part in more activities, improving their physical and mental wellbeing.

More emphasis on community

'I can look after other people, but I don't look after myself – it's wonderful when the community realises you're not able to look after yourself.'

In addition to the importance of individual relationships for people who draw on care and support, both with relatives and with support workers, the importance of a wider network of relationships in communities was identified by participants as extremely important. DPO noted that disabled people often constitute a community of interest, but are not often viewed as being involved in leading and direct support for other disabled people. It was noted that whilst the Church of England is organised around the parish, and therefore has a particular interest in physical communities and neighbourhood activities, the Commission must recognise the importance of communities of interest as a source of support, mutual encouragement, and mobilisation. This theme was raised also in the session with LDE, where the emphasis was on ensuring that people with learning difficulties are embraced and included within the community, which requires making information easily available so that people know what is happening around them, and where necessary can make informed choices about the services they draw upon. Whilst these communities are often formed organically, the Commission was urged to think about intentional ways of creating, supporting, or sustaining reliable communities for people, so that everyone has formal networks that can support them with a variety of activities.

The session with Dementia Voices featured conversations about the sense of isolation many participants felt when they received their dementia diagnosis, with many being given the news by a doctor in what they perceived to be an insensitive way and with little in the way of practical support. One participant shared that, having been unimpressed with the lack of information available to them from medical professionals, they went and found out what was happening in the area and then compiled a list for their doctor, so that others receiving a diagnosis could benefit from the resources they had found. Many people, then, were extremely glad of the support they found in the community, with examples of excellent initiatives, of which there are many across the country, such as music groups, quizzes, and memory cafés. One participant described their gratitude for the fact that one of the lead volunteers at a group they belong to would phone them every week, and if they missed successive calls for any reason would visit in person to check that nothing was wrong. The fact that this care was being shown by a volunteer, who was not being paid to help, made a particular difference in helping the participant to feel known and valued. However, the participants were also quick to point out that just because they have dementia does not mean they have lost interest in contributing to their community too. One participant shared their sense of pride at having led the way in making their local village a dementia friendly place, and another noted that a person does not simply lose their caring instinct once they have dementia. It is often easier for such people to look after others, as they have spent their whole life doing, than to look after themselves.

The session with DPO raised the important reminder that whilst independent living in the community is important, and requires focusing on cross-cutting issues such as transport and employment, there are limits to what can provide be provided in and by the community. There is no point having an accessible transport system if you cannot get out of bed in the morning. A participant who draws on care and support noted that disabled people often want to be part of political and social change, but used the example of climate change as an area in which it is difficult to make personal choices for progress because disabled people tend to drive rather than use public transport. The increased emphasis on community was, however, largely agreed upon as an important focus for a reimagined understanding of care and support. One participant noted that it has been convenient in recent years for the Government to focus on individual rights and the removal of barriers for disabled people, but we have gone backwards in terms of the support offered to disabled people, particularly in terms of education, social care, and the benefits system.

It was also noted in the session with NCVO that whilst communities might be very willing to provide support for people, they are not always the most appropriate administers of care and support. Increasingly since the lockdowns, people are presenting with more and more complex needs. Many people require befriending services, but their needs are too complex for volunteers to be reasonably asked to befriend and the support required should be offered by professionals. However, where appropriate, the session with NCVO highlighted the need to consider that communities enable people to thrive and could provide a cost-effective way of meeting needs in local areas. The importance of early intervention was also emphasised, with lower funds required to help people who have not reached crisis point. A lot of money is spent at the moment limiting the damage that has been done already as opposed to investing in preventative, supportive measures, which involve investing in health, education, and young people’s futures. There is a wider conversation to be had about the fact that whilst the state can fund people to offer practical support, they cannot be substitute for friends and family. Once relationships fall away or break down, there is no replacement for them. Supporting people in their communities is also about supporting strong friendships and family relations.

It was noted that the pandemic had enabled many community organisations to forge stronger working relationships with local authorities. Where these relationships were once often characterised by inflexibility and risk aversion, there is a much more constructive relationship now as community organisations have been seen as reliable and effective partners. The conversation with REF/Faith Action brought out that whilst the NHS is now beginning to engage more with faith communities, there should not be an expectation that the voluntary sector will do things for free, not understanding any of the costs associated. There is significant infrastructure required to put in place policies, procedures, and safeguards to protect everyone’s welfare. There are many different funding pots for community groups, but the funding does not follow the person who draws on care and support.

It was also noted that the support given through mutual aid groups had made a positive impact in many places on bridging social, racial, and religious divides, encouraging people to speak with neighbours and people in the community who may previously have been isolated and meet their needs. A number of participants in the community sector raised the tension between knowing what should be classified as informal support and what should be structured, paid support. It is not always straightforward to know where the boundary lies in enabling people to receive the right support and also have control over their own lives. This point was discussed at length in the Faith Action/REF session, with the danger noted of professionalising support provided at a church/community level, thereby undermining the quality of the work that they do.

A more personalised approach

I wish people would take me as I am and nothing else.’
‘We don’t just want people think about our disability. We want people to see us as an individual person.’
‘Disabled people must be at the heart of their own support.’

At the same time as valuing community and respecting the crucial role that it plays in the realm of care and support, it was noted across the sessions that there should be a more personalised approach, enabling people drawing on care and support to have much more say over the services they use and support they receive.

The discussion with LDE participants drew out the importance of enabling people to have real choices, and encouraged the Commission to advocate for creativity in the solutions and options people might want. There ought to be a more personalised approach where accommodation and services can be matched to the individual, with a greater range of housing choices to support independence. It was also noted that enabling spontaneity, participation, and people choosing how to live, is not just about giving people a say in a tokenistic way, but it encourages creative thinking in resolving issues that people have experienced in their own lives.

It was noted in the NCVO session that social care assessments are about trying to fit a person into existing modes and methods of provision, rather than identifying how to build support around an individual. This approach is all about saying to people that this is the service provided, and you either fit in with it or you do not take it. Challenges were identified in this discussion about where leadership and responsibility should sit, and the challenge of unequal funding and grant provision. One participant noted that they received a disability grant to have their bathroom adapted two years ago, but their council has not yet had the work completed. If it was possible for people to receive the grant themselves, it would be possible for them to get on and make it happen. This would be a much more efficient way of working for the local authority, too. It was widely agreed that money should flow to communities and disabled people without the unnecessary elements within bureaucratic processes that all too often gets in the way, whilst recognising that some structures would always be required.

The issue of consistency was raised again, with people who draw on care and support adamant that they should receive support from someone who recognises and understands their requirements when their usual support workers are unavailable. The session with Livability brought out the importance of good communication. Sometimes when there is help available for people who draw on care and support, they are unaware because it is not communicated in an accessible way. A similar sentiment was expressed during the session with IMPACT, where it was noted that it does not really matter what the system looks like if you do not know about the support on offer. The help to access what exists can be complicated and off-putting, which needs to change regardless of what the future system looks like. The availability of information applies to people working in the system as well as those trying to access care and support.

The session with DPO focused on some of the policy changes that would help disabled people to flourish. One participant noted that, although it is important to support disabled people and remove barriers, even if society was redefined, many people would still need support to do different things (e.g., someone who was blind would still require assistance no matter how supportive the environment and community are). What does this support look like to help people live, flourish, and thrive, who gives the support to people, and how do people who draw on care and support have choice and control over the whole process? DPO also noted that, at every stage, disabled people need to be involved in changing the social care system as equal partners.

Local authorities do not always need to be involved in the assessment process, with people able to get this for themselves if they had the right money and support. Having choice and control should not always require disabled people acting as employers of their personal assistants, who are providing a service. The principle of choosing who comes into your home should not have to require an employment contract. Whether a person’s carer is employed by them, the state, or the private sector, there should be more choice and control over who provides the care and guarantees that it is someone with whom you have an affinity.

A number of participants at the sessions with LDE and Livability noted that the pandemic had exposed wider problems about the independence to which they felt entitled. In particular, the Covid restrictions had prevented people from going out and enjoying activities, even when the laws had changed outside of residential facilities. There was frustration expressed by some participants about the fact that visitors could not enter their residential setting without having had a Covid-19 vaccination, which spoke to a wider frustration about things being beyond your control and having to follow rules that did not apply to the rest of society, even if they were perceived to be in place for the safety and wellbeing of people classified as clinically vulnerable.

This points to a wider issue identified, which is that people who draw on care and support often find themselves unable to go out and enjoy activities, and to develop relationships. One participant told us they wanted to go and watch football at the weekend, but there is not always someone available to accompany them and so they have to watch on the TV instead. It was noted in the NCVO session that people need the freedom make decisions about their own lives and take their own risks, which may involve making mistakes. As soon as you are in the social care system, it feels as though you have no freedom to make your own choices, even if this involves making decisions that others might see as being good or bad for you.

Changes in social attitudes

'I'm not a figure on a piece of paper. I'm not an amount given to purchase care.'
'Sometimes people can't even look you in the eye.'
'The word vulnerable was almost designed to other people.'

As well as practical changes to the social care system, the sessions featured discussion of the need to change societal attitudes, which will then change the landscape for policymaking. A number of the participants pointed out that, unlike the stereotype, social care needs to be about everyone who has a disability, including working-age people. It was noted by participants from Livability and LDE, it was noted that society's attitudes towards disabled people need to change so that people know how to behave and respond when they encounter disabled people. This particularly came through at the session with Dementia Voices, where participants noted that there is a great deal of ignorance about dementia in society. People have a tendency to make assumptions about what those with dementia can and cannot do, with assumptions that it is only about short-term memory loss. Participants also noted that, with a hidden disability, it can become wearing constantly to have to tell others that they have dementia, especially when it is necessary in certain situations in public.

Another participant noted that the move towards automation, for instance at bank branches and supermarkets, is not helpful for people with a range of care and support needs, and speaks to the fact that society is often not geared to support people with disabilities. Society is not geared to support people with disabilities. The lack of accessible, door-to-door transport for people with accessibility requirements featured as a source of frustration on a number of occasions. Taxi drivers often will not help people into their vehicles, or their vehicles are not wheelchair accessible. There is often good provision in the community, but people who draw on care and support cannot always access this.

Another participant noted that people are often not as friendly towards them as they would like, and that even something as simple as being smiled at would make them feel seen and validated when they are out and about. The pandemic has felt like a difficult period for many disabled people who, as was outlined at the session with DPO, often did not feel as though their lives were valued equally because of their impairments or health conditions.

The discussion with DPO led to consideration of a number of policy points as they relate to social attitudes. There was wide agreement amongst participants that there should be parity between health and social care, and it is difficult to understand why they are treated so differently. If there had been more disabled older people in 1948, William Beveridge would not have thought of health and social care so differently. It was also suggested by the DPO that the UK incorporate into law the United Nations Convention on the Rights of Disabled People. Much of the change was seen as being about creating culture change, the solutions for which partly begin with policy changes. If social care is to be seen as something that is valued by people, it may be necessary for social care staff to be registered by a regulator. A participant at the DPO session noted the need for a culture change, with positive attitudes towards disability at all ages. The 'Every Australian Counts' movement was effective in galvanising public and political support for a new system (the National Disability Insurance Scheme), which is a practical example of how you can change attitudes and bring about policy change.

A participant who draws on care and support urged people with an interest in social reform need to campaign more vigorously, having spent years sharing their powerful and important stories only to see little change in return. There was a desire for more campaigning so that the whole population sees and understands what it is like to be in these situations. Concern was raised that the word 'vulnerable' is used far too often to describe people who draw on care and support, which is offensive, othering, and makes people think that people who receive this type of help are somehow different. People who draw on care and support are not inherently vulnerable, and there should be a much greater focus on reciprocal and mutually empowering relationships. There is a lack of representation of disabled people's voices and perspectives at the highest levels, using Parliament as an example. Unless the voices of disabled people are in the corridors of power, there is little hope of reshaping the narrative and services.

Conclusion and next steps

This paper seeks to summarise and capture the main themes and issues that were raised during the Listening and Engagement exercise by a wide range of individuals and organisations.

We are extremely grateful to everyone who responded to the survey, spoke with us, and participated in round tables. The honest reflections and experiences that were shared of care and support have enabled the Commission to draw on a broad range of perspectives and understand both the positives and shortcomings of the current system. We have also benefitted from hearing others' ideas of what a better future might look like and the values and principles that should underpin reimagined care being challenged.

These inputs, alongside the theological and ethical basis, have been critical in shaping the vision. We continue to engage and discuss our work openly. We are undertaking visits to innovative schemes and are doing further engagement to understand what care in action looks like. Our final report will set out how to make a reality of the vision and the actions needed. We are particularly keen during the next phase of our work to engage with those who share our vision to begin to consider implementation and to maximise the impact.

In the survey responses, and the contributions through round table events, one common theme came through loud and clear: the task of reimagining care and support requires a bold vision rather than mere tinkering around the edges. Whilst people disagreed at times about particular issues and policy suggestions, the general consensus, which cannot be ignored, was that fundamental change is required in order to reimagine a vision for care and support in which everyone is enabled to flourish.