



# A Cry for Hope: Why 2021 must be the year for social care reform



## Who we are

The Care and Support Alliance (CSA) was established in July 2009. We represent over 70 leading charities campaigning for a properly funded social care system in England alongside the millions of older people, disabled people and their unpaid carers who need decent care.

Social care is essential in supporting working-age disabled people, older people and unpaid carers to live healthy, fulfilled and independent lives. As well as providing essential support with tasks like washing, dressing and eating, social care also plays a vital role in enabling hundreds of thousands of people to work, volunteer, take part in their community and reduce their risks of social isolation and loneliness. It also employs 1.52 million people and has an annual turnover of £41.2bn.<sup>1</sup>

The CSA believes that not only is there a strong moral imperative for our cause, increased state investment in social care would also be money well spent, helping to save money elsewhere, particularly within the NHS.

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<sup>1</sup> <https://www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/documents/State-of-the-adult-social-care-sector/The-state-of-the-adult-social-care-sector-and-workforce-2020.pdf>

## Social Care During COVID-19

### Those relying on, and working in, social care have been hardest hit during COVID-19.

The pandemic has demonstrated that care workers are some of our most vital key workers. It has also helped shine a light on the fact that many of them work under difficult circumstances in understaffed settings and with inadequate training, all while mostly earning just the minimum wage. Soon into the health emergency, events showed that care homes were not being protected like the NHS and that COVID-19 was able to spread rapidly, leading to a devastating loss of life.

While care home deaths made the headlines, many more people were facing their own challenges at home and had to struggle without services or proper support. Families have also had to take on more caring responsibilities as services scaled back or stopped altogether.

### Funding

Before COVID-19 arrived, social care was widely recognised as being in urgent need of reform and refinancing. Following years of underfunding, as need has increased, councils have had little choice but to progressively limit care to those with the highest needs. As a result, before the pandemic, at least 1.6 million older people and disabled people had some unmet need for care, as well as family carers who did not get sufficient support.<sup>2</sup>

Between 2010/11 and 2018/19, when adjusted for the increase in population size by age, real terms spending on social care per head of the adult population is estimated to have fallen by a mammoth 12% over this eight-year period.<sup>3</sup> The Health Foundation estimate that the amount spent in England per person on social care has dropped to around £324 per person in 2017/18, less than

spending on publicly funded social care in both Scotland (£446) and Wales (£424). More older people requested support in 2018/19 but around 12,500 fewer older people received support.<sup>4</sup>

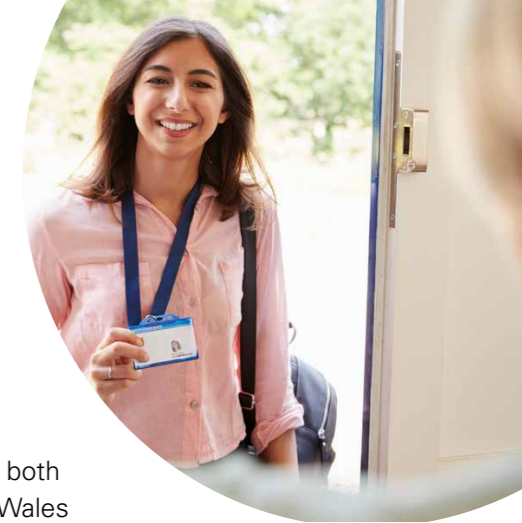
### Reform

Reform is urgently needed and, especially following the pandemic, this is strongly supported by the public. Recent polling showed 7 in 10 voters would see a failure to deliver social care reform as a breach of trust and one third of 2019 Conservative voters say they would be less likely to vote for the Party if a solution on social care is not delivered by the next general election in 2024.<sup>5</sup> It is generally agreed that for reforms to be implemented by the time of the next election they need to be published for consultation at some point during 2021.

### Experiences

To find out the experiences of those who rely on social care, the CSA conducted a survey with over 4,000 people who self-identified as needing care; the results are over the page.

Also in this report the three CSA co-Chairs each write about what they have seen during the crisis from the perspective of the different groups the CSA represents: older people, working age disabled adults and unpaid carers. Their reflections come from their work as senior leaders at the charities for which they work - Age UK, Mencap and Carers UK - as well as with the CSA.



<sup>2</sup> Age UK analysis of wave 9 of the English Longitudinal Study of Ageing, scaled up to the age 65+ population of England using Office for National Statistics mid-year population estimates for 2019

<sup>3</sup> *Health and Social Care Funding*, Health Foundation (2020). Accessed via <https://www.health.org.uk/sites/default/files/2019-11/GE03-Health%20and%20social%20care%20funding%20-%20long%20read.pdf>

<sup>4</sup> <https://www.kingsfund.org.uk/publications/social-care-360/access>

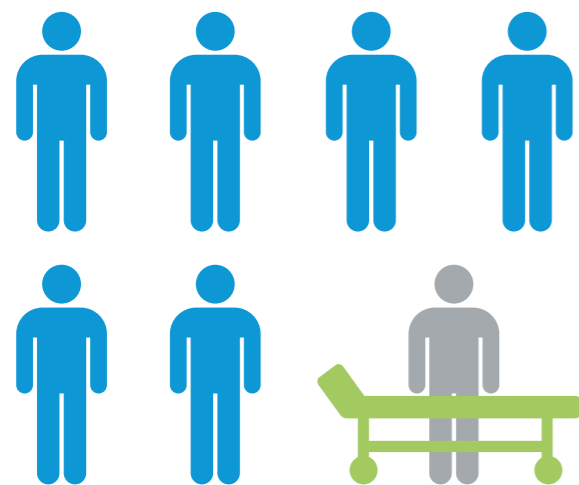
<sup>5</sup> IPPR and Policy Exchange November 2020

# CSA Big Social Care Survey 2020

Care by its nature often happens behind closed doors, so it can be hard to appreciate what people needing care and their unpaid family carers are experiencing. At the end of 2020 the CSA ran a survey to find out more and over 4,000 people responded. Those who responded to the survey were older people, disabled people and unpaid carers. People were asked about the care they received during the pandemic, the impact of not getting the care they needed and what good care meant to them.

## Health

One of the most striking findings was the impact on people's health and the NHS. 1 in 7 (14%) survey respondents said that because of a lack of care they have needed hospital treatment, and more than a quarter (28%) said their health has deteriorated, adding pressure on already overstretched hospitals.<sup>6</sup> A lack of care can have a dangerous impact on someone's health and turn small or emerging health concerns into much bigger ones that require urgent treatment.



**1 in 7**

have needed hospital treatment because of a lack of care

## Many are simply coping with very little help

3 in 10 (31%) of those that had difficulties doing day-to-day activities told us they **never** received the help or assistance they needed, and 1 in 5 (20%) that they **rarely** or **only sometimes** received the help or assistance they need.

A lack of care was a regular theme throughout the survey and when we asked 'What best describes how you feel about the care you have received since the pandemic started?':

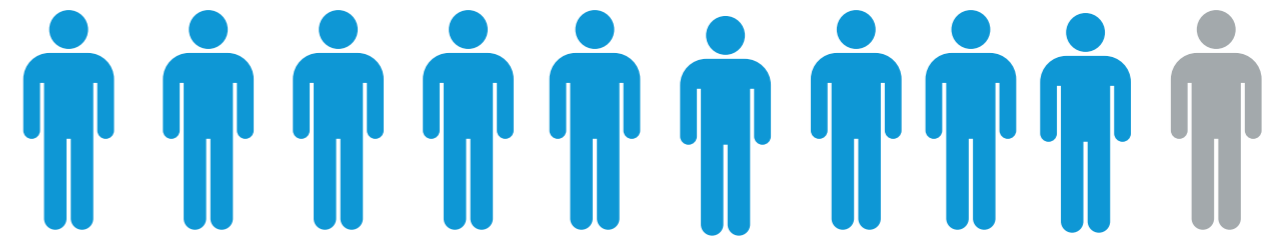
- **3 in 20 (15%) felt neglected**
- **Nearly 2 in 10 (18%) felt scared**

Nearly 1 in 5 (19%) said they had asked social services/their council for help during the pandemic but didn't receive any. And when respondents who selected 'not relevant' were removed from the data, 1 in 3 (34%) said they needed more care but did not receive it and only 1 in 5 (21%) said they received the increased care they needed.

When asked 'Because of not receiving the care you need... have you ever experienced any of the following?':

- **Nearly 1 in 10 (9%) missed medical appointments**
- **More than 1 in 10 (12%) have been unable to get food or shopping**
- **More than 3 in 10 (32%) have felt lonely**
- **More than 1 in 10 (11%) have been unable to work**

A further 1 in 10 (10%) said they were often worried about how to cope and stay safe.



**1 in 10**

- have been unable to work**
- are worried about how to cope**
- have missed medical appointments**
- have been unable to get food or shopping**

## What would have made a difference?

We asked people what would have made a positive difference to their care over the course of the pandemic, and for those who thought something could have helped:

- **Nearly 2 in 5 (39%) said someone to check in on them**
- **Nearly 1 in 3 (30%) said access to day services and respite facilities**
- **1 in 3 (34%) said having more support**
- **More than 1 in 5 (22%) said a simpler process for assessing their social care needs**
- **More than 1 in 7 (16%) cited a change to their care package to meet their changing needs**

## Carers

Nearly 2 in 5 (17%) carers said their health had deteriorated because of their caring responsibilities and separate research from Carers UK has found that during the pandemic 4 in 5 unpaid carers (81%) are currently providing more care than before lockdown and most carers (64%) have not been able to take any breaks at all in the last six months.<sup>7</sup>



**39%**

said having someone to check in on them during the pandemic would have helped



**30%**

said having access to day services and respite facilities during the pandemic would have helped

<sup>6</sup> 4,005 respondents from an online survey open from 26th October 2020 – 1st January 2021. Completed by self-selecting people who identified as needing social care

<sup>7</sup> *Caring Behind Closed Doors: 6 months on*, Carers UK (October 2020). [http://www.carersuk.org/images/News\\_and\\_campaigns/Behind\\_Closed\\_Doors\\_2020/Caring\\_behind\\_closed\\_doors\\_Oct20.pdf](http://www.carersuk.org/images/News_and_campaigns/Behind_Closed_Doors_2020/Caring_behind_closed_doors_Oct20.pdf)

## Adults with learning disabilities

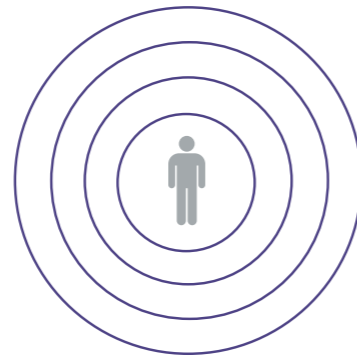
The CSA also circulated an easy read version of the survey and received over 300 replies. 72% of respondents identified as having a learning disability. Nearly 1 in 3 (32%) said they only received **some** of the support they needed and more than 1 in 7 (14%) said they **often worried** about how they will cope and stay safe.

Because of not getting the support they needed:

- 1 in 3 (34%) said they felt lonely or isolated
- 1 in 3 (33%) had to rely on family and friends more
- 1 in 4 (26%) had not been able to see or speak to friends
- 1 in 4 (25%) had not been able to leave the house
- 1 in 5 (20%) had difficulty getting information
- More than 3 in 20 (16%) said their health had got worse

When asked what would have helped during the outbreak more than half (58%) said day services remaining open.

In the summer, Mencap asked over 1,000 people across the UK about their experiences of caring for someone with a learning disability during the crisis. Nearly 7 in 10 (69%) people with a learning disability had their social care cut when they needed it most.<sup>8</sup>



**34%**  
said they felt  
lonely or isolated



**25%**  
had been unable  
to leave their  
house through the  
pandemic



8 <https://www.mencap.org.uk/press-release/i-dont-know-what-day-it-or-what-weather-outside-social-care-cuts-people-learning>

## What does good care mean?

It is clear that the people who rely on care are not getting the support they need. We asked

**"What does, or what would, 'good care' mean to you?"** and the answers included:



**...'Better support for the person I care for would reduce my care and support needs, giving both of us better quality of life.'**

**...'Having control over my life.'**

**...'Everything.'**

**...'Being recognised and appreciated for the care I provide free, valued and being able to take a break.'**

**...'Everything I've been having. I honestly can't ask for any better, my carers paid and unpaid have been brilliant!'**

**...'Someone to make me feel safe. Kindness. Treating me as a person - an adult - not a problem to be solved, or a body to be washed/dressed/healed. Treating me as a whole - physical, mental, emotional - person, and understanding there are a multitude of needs to be met.'**

# CSA co-Chair, and Charity Director, Age UK

## Caroline Abrahams

### Older people and social care during the pandemic.

Older people have had a torrid time during the pandemic, those in receipt of care especially. 9 in 10 who have died so far were over the age of 65 and two in five were living in a care home at the time – many of whom will have died without seeing their family again.

Care home residents are hugely over-represented among COVID-19 related deaths in many countries, not only here, but that's little consolation or excuse. It is widely agreed that care homes and their residents were overlooked by decision-makers in the early part of the pandemic, when all the focus was on protecting our hospitals. It is also beyond dispute that for at least a month in spring, some hospitals discharged patients into care homes without it being known whether they were still infectious with the virus or not. This will have contributed to the rapid spread of COVID-19 across the care home sector, especially as at the time many care homes were struggling to access enough PPE or testing.

**"When we emerge from the pandemic there will be work to be done to rebuild the trust of older people and their families in advance care planning."**

The mistakes made over hospital discharges at the start of the pandemic reflect what has at times been a very clunky interface between the NHS and social care, care homes especially. Before the pandemic, many care homes struggled to access good primary healthcare for their residents and during the height of the first wave some were left to care for very sick and dying older people

without enough clinical back-up or, to begin with, access to appropriate palliative drugs. Blanket Do Not Attempt Resuscitation (DNAR) policies were disgracefully applied to care home residents in some areas as were policies debarring them from access to hospital treatment for any reason. Gradually these problems were ironed out through improved guidance from NHS England and the efforts of clinicians and others locally but we continue to hear occasional anecdotal accounts that give us cause for concern. When we emerge from the pandemic there will be work to be done to rebuild the trust of older people and their families in advance care planning.

There is less information about what has happened to older people who use homecare, but we do know that some rejected care through fear that a domiciliary care worker could unintentionally infect them with the virus, and that others have experienced an erratic or reduced service due to homecare agencies being more than usually short-staffed owing to illness and self-isolation among their workers. There are worries over how quickly older people who said no to services will agree to have them back and what has happened to their health in the meantime; also, whether they will be allowed to have them back or will have to be reassessed as councils struggle to meet even more need than existed before COVID-19 arrived.

Looking to the future, there are many lessons to be learned. The care sector, served by a workforce with sky-high levels of vacancies and churn, and sometimes poor access to good local healthcare, was ill-equipped to deal with a deadly and highly infectious virus. The extreme fragmentation of the care sector continues to make it hard for Government to disseminate instructions and support. The fact that most providers are private businesses sometimes led to hesitation and damaging delays on the part of local and central Government when it came to offering help. The lack of a clear line of sight between the front

line in social care and Ministers – deliberately constructed by previous governments to shield them from complaints about poor quality and under-resourced care - was a huge impediment to accountability and leadership. In other words, it is clear now that the significance of social care as a fundamental public service upon which millions depend every day is entirely at odds with the ramshackle, unstrategic way in which it is funded, organised and structured. Surely that now has to change.

More positively, public awareness of the role of care homes and of the enormous contribution made by care workers has been significantly

raised. Homecare, which already helps many more older people than residential care, remains largely in the shadows for now, but it is likely to be ever more important in the years to come if older people and families are more reluctant to trust care homes. Demand for extra care housing, live-in care and high intensity homecare is likely to increase. As the pandemic has gone on, the scale and depth of good multi-agency working between the NHS and social care has definitely improved in many places, alongside the effectiveness of Government guidance. This provides something to build on in what are bound to be a very challenging couple of years ahead.

**9 in 10**  
COVID-19 related deaths  
have been among the over  
65s

**2 in 5**  
COVID-19 related deaths  
were care home residents



# CSA co-Chair, and Director of Communication, Advocacy and Activism, Mencap

## Jackie O'Sullivan

### Working age disabled adults and social care during the pandemic.

The virus brought social care into much sharper focus.

The early months of the pandemic revealed amazing resilience, creativity and selflessness as disabled people and those who support them adapted to strange new times. People were inspired to innovate and try new things and look out for one another. We saw supported living settings turn into art galleries, garden sheds transform into cafes and some care workers even shielded with the people they support for months on end. The whole social care sector – Government, Local Authorities, providers, families, care workers and the people who rely on care – all pulled together, at times working 24/7 to keep the show on the road.

But, a year on, people are feeling frightened, angry and exhausted. Over the summer when many of us had the option to skip off into pub gardens, many disabled people and their families were left behind in lockdown, and still are, as they wait their turn for the vaccine with the rest of the public. Even during times when restrictions lifted, many were too afraid to start the journey back to normality. And those who did venture back found many of the services they usually relied on no longer available. And they have just reason to be anxious: 60% of all COVID-19 deaths are of disabled people. People with a learning disability are six times more likely to die than everyone else – rising to thirty times for younger age groups. Coupled with the horrifying blanket imposition of Do Not Attempt Resuscitation (DNAR) notices, which in some cases left ambulance crews refusing to take people to hospital, it is no wonder people are angry.

Many have seen their support removed at the

time they have needed it most. Research by Mencap found that over two thirds of people with a learning disability had their social care cut during the coronavirus pandemic, which had a detrimental impact on their mental health, physical health and independence.<sup>9</sup> In addition, a survey by Sense revealed that a third (34%) of disabled people did not have their care or support reinstated when the first lockdown restrictions were lifted.

The social care sector was already fragile and overstretched long before the pandemic hit, but further cuts during the COVID-19 crisis have left disabled people feeling abandoned and worried about their future. The cash injections offered by Government were not sufficient to compensate Local Authorities for lost income and there are alarming reports that many teeter on the edge of bankruptcy. Rationing social care, under the guise of managing the pandemic, is evident, and it is much harder to challenge unlawful decisions. Personal budget accounts have been raided and people have had their care packages reduced on the basis that they have coped during the last year. Coped!

Families, who rely on complicated and precarious support systems as it is, have borne the brunt – stepping in to compensate for what has been removed. And many now lack the energy to fight further cuts to care packages. They report that relationships have broken down, with awful consequences.

Whilst social care has shot up the news and political agenda, it is clear that not many really understand it and how disabled people rely on it to be able to live independently, access their local communities and contribute to society. For most

people – including many involved in the response to the pandemic – social care is older people in care homes. PPE drops, testing programmes, visiting policies, vaccination rollouts were all based on Registered Care Home data which leaves out most working age disabled adults. And even where people understand and acknowledge this, there do not seem to be the mechanisms in place to reach every part of this complex and fragile ecosystem. Most disabled people receive care in communities – in supported living settings or their own homes – and their needs are different and often greater than personal care. If social care is the poor relation to the NHS, then supported living is an even poorer relation to the care home.

"Personal budget accounts have been raided and people have had their care packages reduced on the basis that they have coped during the last year."

As a country we understand now, more than ever, how vital social care is to people's well-being. All that we have learned from COVID-19 is handing Government a licence to do something really bold that could fix social care for the next generation. We need to re-imagine social care, resource it properly and give a pay rise to all those hard-working support workers and carers who have held it together during the pandemic.

## 6 in 10

COVID-19 related deaths are of disabled people

## 3 in 10

disabled people did not have their care or support services reinstated after the first lockdown



<sup>9</sup> <https://www.mencap.org.uk/press-release/i-dont-know-what-day-it-or-what-weather-outside-social-care-cuts-people-learning>

# CSA co-Chair, and Director of Policy and Public Affairs, Carers UK

## Emily Holzhausen OBE

### Unpaid carers during the pandemic.

Caring for older, disabled or chronically ill relatives or friends has always been part and parcel of millions of people's lives. In normal times, the care that people provided was a staggering £132 billion a year – millions of hours providing essential unpaid support. During the pandemic, their support has been valued at £530 million each day – the same value as six months of funding in the Infection Control Fund.<sup>10</sup> For many, this has come at great cost to carers' wellbeing, health, work and relationships – because of a shortage of care, a lack of recognition and little financial support.

Whilst it was hard for millions providing unpaid care before, nothing could have prepared us for the extreme impact of the pandemic when care and support, which was already in short supply, suddenly dried up even further as services closed and retreated or carers were simply too scared to have people in the house. Some services have continued throughout with care staff and volunteers going above and beyond to support families and where this did happen, families have said that it has been a lifeline. But more day and respite care services have closed or reduced than have continued.

As a result of the shortage of care, millions of carers have gone without any breaks at all since March 2020 and even those caring around the clock are doing more – more medical tasks, more supervision, more education, more physical tasks, with less sleep and, for many, greater financial anxiety to cap it all. Carers are, quite simply exhausted and at the end of their tether.

Just imagine if they had not been able to care. The NHS and social care, already under pressure, would not have been able to cope. If just one in 100 had not been able to care, services would

have been quickly overwhelmed, with devastating consequences. The Government needed people to care, and they did, but at what cost? And have carers received the recognition and support they needed and deserved?

The numbers caring rocketed during the first national lockdown from an estimated 9 million to 13.6 million. While we would not expect these levels to continue, caring at this intensity has come at the expense of health, wellbeing and livelihoods. It is neither sustainable for families, nor economically viable for the country.

Since the beginning of the pandemic the levels of anxiety and exhaustion have become all too familiar. Recent surveys have found carers at breaking point, fearful of the future and how they will manage. Carers providing substantial care already had poorer health and wellbeing and this has got worse during the pandemic, with half saying that their mental health and/or physical health had deteriorated. Just because care happens behind closed doors does not mean it can be forgotten. There will be long term impacts on carers' health and their ability to care, and we need quick action to ensure carers get the support they need so as to minimise the impact.

Integration between health and social care cannot work if we don't have a shared and common understanding of carers, underpinned by law. Social care law sees carers as having their own needs and support. Laws for the NHS only see patients and not the millions of carers providing support with greater integration on the horizon, it's time to reset that balance and recognise carers better within the NHS.

During this pandemic more people have become

carers and are providing more care than ever before. Social care reform needs to be delivered in 2021 and has to ensure carers are better able to care and to get the support they need. The foundation for the future must be good quality social care, some of which should be free at the point of delivery. This would reduce inequalities, increase jobs for workers, allow many more carers to juggle work and care and give people and their families strong, positive choices. Evidence from other countries suggests this will also strengthen the market.

Carer's Allowance must be on the Government's list for significant improvement in any discussion of social care reform. Over 70% of claimants are women and it is the lowest benefit of its kind at only £67.25 a week, for which a minimum of 35 hours of care must be provided.

Investment in good quality care, combined with a new vision for supportive workplaces, could transform the capacity of people with caring responsibilities to juggle work and care. Good quality social care has to be considered in the

same way childcare was – enabling families to juggle work and care. It also provides essential support for disabled people wanting to work as well, levelling up for everyone.

Reflecting on the lessons from this pandemic, it is clear that there is an opportunity to create and deliver a new vision for social care, with carers at its heart. There is myth that formal care replaces the traditional role of the family. There is no evidence for this. Families who have great care don't stop caring, it's just that the type of caring changes from providing personal care to more social contact – which is how people want to live their lives. Even countries with better developed care systems still rely on families. They can never be wholly replaced, but with the right investment in social care we can offer disabled and older people and their families and friends who care a better deal, more choice and better outcomes. We cannot continue with a situation in which caring is behind closed doors and carers feel ignored and invisible. It is time to act.

## £530m

the value of informal care given each day during the COVID-19 pandemic

## 9m to 13.6m

growth in the number of informal carers during the first lockdown



<sup>10</sup> *Unseen and Undervalued*, Carers UK (November 2020). [https://www.carersuk.org/images/News\\_and\\_campaigns/Unseen\\_and\\_undervalued.pdf](https://www.carersuk.org/images/News_and_campaigns/Unseen_and_undervalued.pdf)

## Beyond the Pandemic: refinancing and reforming social care

So much pain, sadness and loss. Also, a feeling at times that people in receipt of care and the workers who care for them, and their unpaid carers, do not count for much. All are victims of a neglected apology of a 'care system' that is crying out for refinancing and reform. This was sorely needed before the pandemic struck and all the more so now. Nothing will bring back the tens of

thousands of people in receipt of care, mostly in care homes, whose lives were cut short by our national failure to act quickly enough to protect them, nor the hundreds of care workers who died either. However, decisive Government action during 2021 to restore social care, at last, to a position of sustainability and decency would be some atonement at least.

### What the CSA wants to see

The Government must provide immediate and sufficient funding to Local Authorities and to care providers to stabilise the social care system between now and the end of 2021 – a time when it will be under extreme duress from the pandemic and its fall-out. We support the call of the Health Foundation for an immediate cash injection of £12.2bn to recover peak spending and ensure a pay increase for staff.

The CSA wants to see whole system change for social care, based on a number of core principles which are set out below.

This Government has made it clear that it sees funding reform as central and that its preferred way forward is to implement a version of the 'cap' on catastrophic care costs which was developed by Sir Andrew Dilnot's Commission ten years ago and enshrined in the Care Act 2014, but not so far actioned.

The CSA recognises that it is important to solve the problem of catastrophic care costs but believes that this is only one of a number of weaknesses bedevilling social care, all of which need to be tackled if we're to do right by older people, disabled people and unpaid carers.

The Prime Minister promised to 'fix social care once and for all' when he entered office but implementing a cap on catastrophic costs, even if it is pitched generously, cannot possibly achieve this on its own. Especially after this terrible pandemic the Prime Minister should stand by his word and that means bringing forward a package of measures related to our principles to:

- **Fill the funding hole in the means-tested system**
- **Reward and strengthen the care workforce**
- **Improve quality and choice of care for all**
- **Support unpaid carers**

In summary, the CSA believes that social care is in desperate need of transformational change and refinancing, but a 'cap' on its own will not deliver it.

## CARE & SUPPORT ALLIANCE

1

The cost of care is pooled on a compulsory whole (adult) population basis, funded through taxation.

2

Care is free at the point of use.

3

There is an independent, standardised national eligibility threshold and assessment process for social care, to prevent rationing.

4

Eligibility is set at a 'moderate' level to enable those in need of community and preventative support to access it and to encourage more focus on prevention.

5

The care and support needs of working age disabled adults and older people are both addressed.

6

There is increased support for unpaid carers through more breaks and better core support, including helping carers to juggle work and care, and increased Carer's Allowance and other carers' benefits.

7

There is a new deal for care staff, beginning with an immediate pay rise and including an agreement to move to parity with the NHS for the same roles, by a set date; a revised career structure; better training and development opportunities; and registration.

8

Social care must have parity of esteem with the NHS and reform needs to ensure smooth working between social care services and other agencies, including the NHS and housing.





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