

“Don’t ever call us unskilled again!”

Learning from the experience of Support Workers during Covid-19.

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Published by Paradigm 4th August 2020



Special thanks to the following for their support:

Dr Christina Schwabenland (University of Bedfordshire) and
David Towell (Centre for Inclusive Futures)
for your support in writing this report.

Thank you also to the following organisations for support the
publication of this report:



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Foreward

Over the last 5 years Sally and Jo (from the development agency Paradigm) have focused a lot of their work on raising the profile of what good support looks like in society, particularly for people with a learning disability and/or autism.

Good stuff happens in social care every day. Here at Paradigm we have co-created (with self-advocates, families and supporters) the Gr8 Support Movement* to connect Support Workers across the UK to share, learn, celebrate the work they do and elevate their profile.

The Covid-19 pandemic has brought all of this into extreme focus. As lockdown was implemented, we noticed an increase in activity in the Movement, with Support Workers seeking peer support and sharing how they were coping as the crisis hit. It is these Support Workers who motivated us to create a qualitative survey that would capture their experiences and learning during the Covid crisis, and importantly, to use these to guide and embed the best in future practice.

This report draws together the observations and insights of 118 members of the Movement and beyond. These Support Workers work with people who have learning disabilities and/or autism. Most of the support represented in this survey relates to people living in family homes, their own homes or small shared homes (social care includes care homes too, but is so much more – as well as where people live, social care touches other parts of people's lives that enrich us – employment, relationships, education, being in and part of the local community).

It's time to reframe the image of social care, to emphasise social and why it is important. A definition of social: “seeking or enjoying the companionship of others: friendly, sociable; gregarious.....living or disposed to live in companionship with others or in a community, rather than in isolation” (Dictionary.com) offers an insight into what one support worker calls a hidden industry. These hidden workers have been on the frontline during the pandemic and their stories are a moving expression of how Support Workers have stepped up, flexed up and adapted to the Covid crisis. These Support Workers' determination has made a huge difference. They embody the spirit of what good support should always look and feel like, working alongside people to have good lives – in settled times and during pandemics.

We have learnt extensively from engaging with and listening to these Support Workers. We are holding up their words as a powerful testament to what is possible and should be done as we emerge from the world's first major pandemic for nearly 100 years. We have hope, we have each other, we have good people working in social care – let us build on this together, alongside people who are supported and the social care system itself to keep doing what works, embed the newly discovered ways of working and getting rid of what doesn't work.

* The Gr8 Support Movement was founded (by Paradigm) in 2017. It is a pioneering way to lift the voice of Support Workers across the UK to share, learn, grow, debate and celebrate the work they do. It is founded on the essential characteristics of support that over 350 people with a learning disability and/or autism and their families said they wanted their Support Workers to have. These were distilled into eight qualities of a great (Gr8) Support Worker: 1. Adventurous. 2. Friendly. 3. Encouraging. 4. Supportive of my loving. 5. Connecting. 6. Advocating. 7. Respectful. 8. Resourceful. Join us at: www.paradigm-uk.org.



“...When the crisis hit, it was the low paid people we relied on. Not the rich or famous. We need to learn about what is important... PPE stocks need to be maintained, investment into care and NHS systems continued. A pay scale which represents the role, not one that represents the interest society wishes to pay to a hidden industry.”

(Please note all quotes in grey are direct quotes from the survey)

Introduction

This report is based on responses from The Gr8 Support Covid-19 Snapshot survey which invited Support Workers across the country to capture their experiences, thoughts, ideas and learning during the pandemic and share these with the nation.

The report captures:

- how support workers responded during the pandemic with thoughtfulness, creativity and dedication.
- some key messages and 'must haves' for moving forward beyond the pandemic.
- the plea of Support Workers to be valued and recognised as essential and highly skilled members of the Social Care workforce, not just now but as society moves forward.

We wanted to give a voice to Support Workers who do not generally get the opportunity to tell their story. We wanted to give them a platform to do this.



“As per usual, Support Workers have a vital voice, they have proven to be highly skilled, caring, kind and resourceful - Powers that be MUST continue to listen and encourage more creative ways of support and value the role.”

Context

For many years Social Care has been underinvested in, undervalued and invisible to many. Many members of the public are unaware of the importance of Social Care and how it is a lifeline to millions of people across the UK from the moment of birth to the moment of death.

This invisibility of social care amongst the general public has meant that horrific cuts to services and budgets have been largely unnoticed and unchallenged.

* Personal Assistants are people employed directly by an individual to provide some of their care and support.

Even some of our elected representatives have assumed social care is part of the NHS and free – neither of these are true. This has led to it's amazing workforce (that includes Support Workers and Personal Assistants *) being overlooked, underpaid, unappreciated and even referred to by senior ministers in the Government as 'unskilled'.

And then the pandemic happened.

What we have witnessed during these unprecedented times is:

- Groundhog Day - Social Care being treated as an after-thought.
- Some paradoxical moments where Support Workers were initially overlooked but eventually seen as Key Workers who were highly valued, kept the country functioning and then encouraged to get a CARE badge.
- No additional investment in Social Care to keep functioning and moving forward.
- The Prime Minister suggesting that providers of care were in some way to blame for the high number of deaths.
- Support Workers offering highly skilled and innovative support in incredibly challenging times, whilst being conscious of the risk to themselves and their loved ones.



“Do we value Social Care?”

In total the number of people working in care and support is estimated to be in the region of 1.5 million. It is the largest workforce in the UK. A large number of these people work in more traditional settings offering care to people in care homes supporting older people. It is worth noting that much of the media during the pandemic has referred to 'Care Workers' and represented social care in one dimension - large Care/Group Homes for older people.

This report focuses on the smaller proportion of this workforce who are Support Workers working alongside adults with a learning disability and/or autism (of whom there are about 1.5 million) living in the UK.

Semantics matter here - Support Workers have a significantly different role to that of a Care Worker. The role of a Support Worker is to support people to live, work and thrive in their community as equal citizens. This includes, where required, being skilled at supporting people with complex disabilities who may have unique communication styles and a range of behaviours communicating their emotions. Support Workers who responded to our survey typically support individuals: in their own home (where they live on their own or with a small number of other people) or at home with their parents. The support offered can range from checking in occasionally, through to a few hours a week, to 24hrs support seven days a week.

* Personal Assistants are people employed directly by an individual to provide some of their care and support.

Over the past decade, Support Workers have told us that their role is often misunderstood and in danger - with cuts to budgets leading to less time with individuals - of becoming a solely 'task' orientated role rather than a role that supports people to live good, ordinary lives. Examples of 'auction sites' for commissioning support and the dreaded 15 minute 'care' visits emerged. These are not fit for purpose for individuals, their families or the workforce.

It is a national scandal that people with a learning disability experience greater ill health and die, on average, 15-20 years sooner than the general population. In June 2020, Chris Hatton's [blog](#) highlighted statistics relating to the peak of the pandemic and reported that in the general population... *'less than 40% of weekly deaths were attributed to COVID-19. For people with learning disabilities, approaching 70% of people's deaths were attributed to COVID -19.'*

We are still learning about the full impact of the virus, particularly on those with a learning disability and/or autism. Reports are revealing that people are more likely to get ill and possibly die from Covid-19 when they live in larger settings. Smaller settings are safer (['Covid-19 outbreaks up to 20 times more likely in large care homes, study finds.'](#) 14 July 2020). This data must be considered when decisions are being made about the prioritisation of testing.

Care homes have hit the news and the rest of the Social Care sector has been excluded from guidance and easy access to testing. A public inquiry is needed to understand how many of these deaths were avoidable and no doubt due to pressures across the health and social care sector.

The method

Working with Dr Christina Schwabenland from The University of Bedfordshire, Paradigm created a qualitative survey for Support Workers that opened on 5 May 2020 and closed on 19 June 2020. It was shared via social media with The Gr8 Support Movement and other Support Workers across the UK who support people with a learning disability and/or autism.

The survey asked the following:

1. What has concerned you most during this time?
2. What has helped you most during this time?
3. What would have helped you, or could still help you, in your role during this time?
4. As a Support Worker during the Covid-19 pandemic, what are you most proud of?

5. Looking ahead, what learning should we value and take forward about the ways in which Support Workers have responded to the crisis?
6. As a Gr8 Support Worker what message would you give to the country at this time?
7. Anything else you would like to share with us?

We received 118 responses.

The respondents

Of the 118 respondents:

- 73% were Support Workers (people employed by organisations to offer support).
- 5% were Personal Assistants (people employed directly by an individual to provide some of their care and support).
- 22% were Team Managers/Team Leaders who directly manage teams of Support Workers and also provide direct support.



Reflecting on the pandemic means being honest about the challenges, celebrating what went well and learning...



“We have helped each other cope with a lot of fear and anxieties due to the situation, and these are further stressed with the worry of the people we support contracting Covid-19. I am proud of myself and my colleagues for keeping on going with our role and trying to make this time as enjoyable for the people we support as possible.”

The challenges

Six months ago, many of us would not have believed that a world-wide pandemic would change our lives so dramatically. Being hit with an abrupt lockdown across society, is inevitably going to cause harsh challenges and confusion.



“It's impossible to know what will happen. All the preparations in the world can not foresee what an autistic adult will do or how they will cope when their whole world and routines are stopped or changed.”

People found it hard not having clear and timely guidelines to inform the way they should support individuals to keep everyone safe and well. As you can see in the table on the next page, just over 58% of respondents were confused by the messages from the Government.

There was an appreciation of employers trying to provide guidance promptly, but this proved difficult as the Government and in turn, Local Authorities, were not providing what they needed to do this. When the information was eventually produced, Support Workers spoke of the difficulties in knowing where to find it – they wanted to be confident that they were using the most up-to-date guidance. Part of the challenge was that this information changed on a weekly, if not daily basis.

What has concerned you most during this time?

Answer choices	% Response	No' of people
• The people I support might contract the virus	84.62%	99
• People I support feeling isolated and missing their friends and family	73.50%	86
• I could take the virus home to my family	68.38%	80
• My colleagues might contract the virus	63.25%	74
• Not being able to give dates of when lockdown will end	61.54%	72
• I might contract the virus at work	60.68%	71
• Government messages being confusing	58.12%	68
• Some of the people I usually support only getting phone/video calls	41.88%	49
• Keeping motivated	38.36%	45
• I spend less time with some of the people I support	37.61%	44
• Supporting people to stay well and active	36.75%	43
• Supporting people with their fear of illness, death and dying	35.90%	42
• Emotionally support my colleagues	35.90%	42
• Testing for Covid-19 not being available	34.19%	40
• People struggling with using phones, laptops etc independently	29.91%	35
• Lockdown increasing people's dependency on paid staff	28,21%	33
• Not being sure what Protective Personal Equipment (PPE) to wear	21.37%	25
• Not enough PPE available	21.37%	25
• Limited support/supervision for me	11.11%	13

Total Respondents 117

Support Workers wanted to be able to explain what was happening to those they support and this was a real challenge as the government did not provide Easy Read information at timely points alongside the regular updates.

They spoke of the mishandling of Social Care when the Government released people from hospital back home without being tested for the virus. Staff spoke of their real anxiety and fear of the virus being spread to others who shared their home (as well as them and their colleagues). Tests were not available to people living and working in supported living settings. They highlighted their extreme concern at being held responsible for any spread.

There was a lack of faith and anger at the Government's response and annoyance at the poor investment in social care.

“I believe the government response has been totally incompetent and negligent leading to the unnecessary death of thousands of people.”

Many families suddenly lost their Support Workers who had been previously supporting them on a weekly or daily basis at home – families who rely on these Support Workers. This ‘pause’ in support continued for these families throughout the whole of lockdown and for many, as we write this, this ‘pause’ still remains.

“Also, amazing shout out to the families who have lost their PAs during this time and are doing their best!”

For Support Workers who were part of an organisation, one challenge was ensuring that, as much as possible, there was a consistent team supporting a person. Having fewer staff coming and going from a small shared house/flat or an individual’s home made it easier to minimise the risk of infection.

“Supporting someone who lives independently has made it possible to keep her risk minimal and ours. We have created a small bubble of interaction. In... a [large residential setting] home, the risk and ability to keep her safe would have been scarily high”

With high levels of staff isolating, this was a real challenge, leading to people working extra shifts, sometimes with people they didn’t know. Support Workers talked about being exhausted and needing a break.

The nation heard about the challenge of getting the right Personal Protective Equipment (PPE). Unsurprisingly, this was raised as a real concern by a number of Support Workers who said that, not only were they short of PPE at times, but clear guidelines on how to use it were not provided. This was a challenge for those who do not typically use PPE in their roles.

Support Workers worked hard to help people maintain as much independence outdoors as possible, but the behaviour of others in the community not following the Government guidance led to confusion and anxiety for some of the people they supported and for the Support Workers themselves.



“...members of the public not adhering to government advice and the restrictions put in place as it creates a grey area for the people I support and they then get confused with where they stand.”

There was real frustration from Support Workers about the fact that it was so hard to get grocery delivery slots. It became clear that, whilst registered care homes were on a priority list with all the supermarkets, people living in supported living settings (where people have their own tenancy on their own or with housemates* and receive the support they require to live full lives), had been completely overlooked. This created further stress and anxiety for the workers as it meant that stretched Support Workers were also having to go into supermarkets.



"There were special 'passes' accorded to some care homes to have grocery delivered to them as a priority. Our home was not on that list so we could not do online shopping as there were no delivery slots or 'Click and Collect' slots available in most cases."

Support Workers spoke about the challenges of the direct impact on those they support. People really struggled to understand why they couldn't see their family and friends, the changing rules on social distancing and all the uncertainty. People also started to lose some of the skills they had developed over the years e.g. to shop and travel independently. An additional challenge was accessing resources and activities that matched the interests, skills and ability of each person.



“The people we support are quite independent and they don't want to do some of the things that have been made available as they see them as immature.”

During the pandemic, it felt like everyone moved into the world of Zoom and WhatsApp and this presented a real challenge for many people with a learning disability and/or autism. Many did not have access to suitable mobiles, tablets, computers, apps or access to WIFI and the money to pay for data. Many did not have the skills to be able to use them if they were available. The challenge to Support Workers was not only to find the resources people needed to connect, but to make the time to be alongside people in using them (in a time of high staff sickness, shortages and changing priorities in their roles).

* (See Reach Standards: <https://paradigm-uk.org/what-we-do/reach-support-for-living/>).

A few Support Workers were disappointed that senior colleagues did not fully comprehend the realities of their day-to-day work and this did not reassure them in their demanding role. One Support Worker described their managers as, '*managers leaving the premises like rats on a sinking ship*'.

Support Workers found it difficult not being able to spend time with their peers beyond the limited, formal team meetings. This alongside minimum supervision for some, led to some Support Workers feeling isolated. They would have valued time to reflect, learn together, reassure and support each other.

Working under these severe pressures, Support Workers were aware that some of their peers had been furloughed, receiving 80% of their pay, alongside other entitlements e.g. accruing annual leave. This felt unfair when they were working, often extra shifts, and in risky situations without any bonus, additional leave or hazard pay.

Rising to the challenges



"Dedicated staff and management teams carried on even though the world stood still around them."

Do you remember how you felt, the raw emotions you experienced and the sense of vulnerability when we were told the whole country was going into lockdown overnight? When we could potentially be exposed to a virus that would threaten our lives and the lives of those we love?

Support Workers told us of the fear and anxiety they felt for themselves and their loved ones. The fact is, they still had to go into work and couldn't lockdown in the way that many of the population did.

At a time when leaders or managers of organisations were fathoming out (almost overnight) what the way of working needed to be during this time and adapting policies and guidelines in line with this, Support Workers were there directly alongside people with a learning disability and/or autism. They were helping people manage their fear and anxieties, navigating difficult changes to routines of individuals and/or groups of people, supporting people to withdraw in a sensitive way from physically seeing and being with their family and friends. All this whilst gauging how to keep people coronavirus free and emotionally well.

It is important to remember that whilst the people being supported would have experienced a whole range of emotions just like anyone else, due to the nature of their learning disability and/or autism, many found comprehending and adjusting to these pressures profoundly difficult and challenging. Support Workers showed acute skill, innovation, resilience and dedication to individuals at this time.

The depth, range and nuance of skills required to navigate all of the above is quite astounding. Sadly much of this still remains largely unnoticed in society.

But Support Workers noticed it. They were proud of their skills and as one Support Worker described here:



“Support Workers do not just ‘clean, dress, feed and medicate’, they support people to live their best lives - to understand what’s happening around them, to live as independently as they possibly can - including learning and trying together with the people they are supporting, new skills and adventures. They have fun with the people they are supporting and make connections. And they are dedicated and professional in what they do.”

Support Workers spoke with pride about how they had developed new ways to help people stay connected with those they love and care about. In many ways, people’s worlds opened up and new connections were made as a result of the many opportunities that Support Workers and self-advocates made possible. These virtual connections via WhatsApp and Zoom, connected families, friends and new people across the country. Whether it be an online chat, coronavirus briefings, Zumba classes or quizzes, Support Workers worked alongside people to create these possibilities. This often involved the Support Workers having to advocate on behalf of people to ensure they could get WIFI and access to the IT resources e.g. tablets, computers and the necessary apps or programmes.



Most proud moment... "When I managed to get a three-way WhatsApp video with two people I support. It was the first time in a couple of months that they had seen someone else from the day centre."

Support Workers described the skilled way in which they involved and walked alongside the people they were supporting, helping them understand the ever-changing restrictions of lockdown and their worlds. People used Easy Read information (when they could find it) but also skilfully broke down the information they were being given in a way that the people they support could understand.

Support Workers also used their skill and knowledge of individuals to notice how individuals communicated confusion, anxiety or distress non-verbally and responded to this in a way that offered reassurance and understanding.

A number of respondents spoke of their great pride and relief at the fact that the people they supported had not contracted coronavirus and that this was due, in part, to them learning and implementing protocols that prevented transmission. One person drew attention to the fact that their organisation avoided using agency staff to ensure a consistent team wrapped around the people they support to reduce the risk of infection. 69.49% of Support Workers (as shown in the table below) felt that knowing how important their work was in ensuring people stayed well, helped them during this time.

What helped you most during this time?

Answer choices	% Response	No' of people
• Knowing how important my work is in ensuring people stay well	69.49%	82
• The good weather	67.80%	80
• Sharing new ways of working, ideas and activities for supporting people	64.41%	76
• My colleagues	60.17%	71
• Support from my manager	54.24%	64
• Updates from my employer	52.54%	62
• Having access to the Personal Protective Equipment I need	46.46%	56
• National recognition of the value of social care and key workers	38.14%	45
• The freedom/opportunity to respond creatively	38.14%	45
• Spending more time with some of the people I support	26.27%	31
• The response of, and support from, members of the community	24.58%	29
• Support from the families of people I work with	24.58%	29
• Government messages	12.71%	15
• Information on social media	15.25%	18

Total Respondents 118

Whilst one person said that this pandemic 'highlighted those that really do just do the job for money', the overwhelming story was the sense of skill and commitment that Support Workers had to their role and their pride in 'being there'.



Most proud of ... "Still making sure I turn up to do my job with a smile and a brave face no matter how much fear I may carry with me."

Numerous people spoke with great enthusiasm about the team spirit amongst staff that helped them find ways of getting through this pressured time. It helped them work through their own fears, grow resilience together, cope with change, minimise transmission of the virus, know when and where extra support was needed and generated some unanticipated creative thinking in the time of a crisis. With a few strong exceptions, Support Workers felt well supported and proud of their organisations.



“My boss has coped remarkably well due to the team being close.”

About a third of respondents talked about remarkable creativity that manifested through the way they supported others during the lockdown. During this time, Support Workers helped people connect through new mediums, created activities such as craft activity packs, delivered food, created online quizzes and supported people to maintain as much independence as possible, all whilst having ongoing conversations about what was going on with the pandemic. It is important to consider here that when Support Workers worked alongside to do all of the above, they had to be mindful and skilled at the fact that the people they were supporting had a range of abilities and interests. For example, what might be accessible to one person, might be child-like to another. This really highlights the importance of developing a relationship with the person you support that ensures a deep understanding of who they are, what they need, what they enjoy and how they communicate this.



"My colleagues...have been outstanding in their approach. Showing a willingness to adapt and think outside the box. To provide a service and calmness our clients need/needed."

Support Workers felt a sense of freedom, empowerment and pride in being able to work this way.



"... we are professionals who have lots to offer. Support our creativity and let us use this. Ultimately pay us what we are actually worth."

There was a sense that, before the pandemic, rules, policies and regulations overly restricted the way people offered support and eclipsed more natural and creative ways of being.



“Often managers that are not on the frontline forget what it is about and are governed by their policies - sometimes I think it needs reminding that they need to step out the box and let it all go a little bit wild.”

Over the last decade or so, there have been huge cuts to Social Care budgets leading to many Support Workers having less time with those they support and being under tremendous pressure to focus on ‘tasks’ to be completed. The different way in which Support Workers spent time with those they support during the pandemic, enabled them to experience the ups and downs of relationships which opened up new knowledge, capacities, interests, and new possibilities to try.

Whilst it was an extremely stressful time, respondents clearly enjoyed growing their relationships with those they support during lockdown and being trusted to respond in a way that was right for each individual. It was an opportunity to bring their whole selves to work.



Most proud of... “Just being me and the opportunities offered in terms of creativity and actions that might not have happened.”

Support Workers also reached out across the country to connect with and share their experiences with other Support Workers:

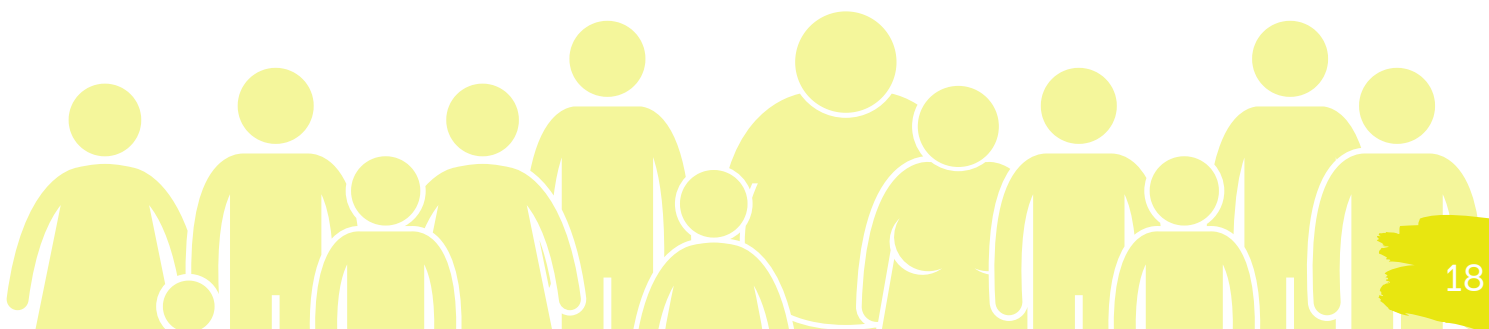


“I have loved interacting with other organisations and their clients through the Gr8 support network in particular The Gr8 Chat and Brews.”

All of this must be read within the context of how local communities reacted in this very challenging time. Members of the community volunteered their time and support spontaneously to help with shopping, being part of online video calls and showing random acts of kindness. This kindness was welcomed and, in contrast to times before, where DBS checks or heavy risk assessments would have delayed this offer of assistance, Support Workers embraced how their community naturally and spontaneously came together.



“Let’s keep the community spirit at the front of our thoughts as this is what gets us through difficult times.”



Valuing the skilled role of a Support Worker



"Please don't just value key workers during a pandemic, they should always be valued and respected not just by the public but by the government."

In February 2020, a Government Cabinet Member Priti Patel, described 'Care Workers' as 'unskilled'. At workshops that Paradigm facilitated during this time, Support Workers vented their anger, resentment and sense of injustice at this. They felt it gave society a misrepresentation and incorrect understanding of the complexity of their roles as Support Workers and that of their colleagues.

There was further insult to injury, when Matt Hancock, The Secretary of State for Health and Social Care, thought it was a good idea to offer Care Workers a green 'CARE' badge – one that each person would have to pay for. Support Workers found this offensive.



"No stupid badge!!"

Whilst NHS staff were the focus of attention and appreciation throughout the pandemic, it took a number of months before those working in Social Care were recognised and valued, and even then, it only really referred to people working in care homes supporting older people. Many Support Workers spoke of their pride in being seen as essential Key Workers (who kept the country going).



Most proud of... "Being recognised as an integral part of our care/support structure. Presently it only appears that the NHS are the recognised carers but Support Workers who are working just as hard with vulnerable clients who may lack capacity and are challenging seems to be the unsung heroes and unrecognised. Support Workers/PAs should be financially rewarded with a decent pay band and increase."



"The job is hard, but we are willing to get on with it, but we need to be on par with the NHS, not seen as a burden."

Support Workers appreciated how society was trying to support them by allowing them to jump queues in supermarkets and shops and being clapped on a Thursday evening. But they were clear that clapping was not enough.

Support Workers are a workforce that are notoriously underpaid. It is hardly surprising that a third of respondents spoke of their wages being too low and not reflecting the range of skills and dedication that their role requires.

“

"Whilst we do the job because we care, Support Workers are among the lowest paid workers we have been frontline during the crisis and wages should reflect the responsibility we take on...so, wages need to be higher."

“

"We urgently need to pay Social Care workers much better. This is a vocation and we should all unionise and fight for financial recognition."

In connection with pay, Support Workers spoke of the need to acknowledge the extreme circumstances the pandemic threw them into. They felt that this should be acknowledged with bonuses, hazard pay, additional leave or a one-off reward.

In addition to this, there was a recognition for there to be investment in emotional and mental health support:

“

"I feel some have struggled in some ways but have dealt with this by talking to staff and mental health support."

“

"It would be good for companies to focus on creating and maintaining a great staff team that work hard but also feel valued. Also, I think it is good to take forward a focus on supporting everyone including people we support and staff with mental health struggles which will have developed or worsened due to the pandemic. Moving forward everyone will need a lot of support to develop as life continues to change again."

Having access to training (beyond the minimum) to develop their skills, competencies and leadership abilities with a view to furthering their career was considered to be another way to show value to the work force.

“ “People work hard in this job and you take out as much as you put in. The right companies will offer good training and opportunities to work your way up through the company.”

The diverse range of skills and commitment demonstrated in the survey response, highlight how important it is for society and the Government to truly value the complex and professional role of Support Workers within Social Care. We must lift the voice and presence of Support Workers and Social Care which are too often unnoticed or taken for granted.

“ “People who offer their time, energy and attention to help vulnerable others are an asset to society and should be valued as such. Let's see a shift away from viewing Social Care as a tiresome drain of resources to viewing it as a valued and essential part of society.”



Key messages in responding to the pandemic



“...when the crisis hit, it was the low paid people we relied on. Not the rich or famous. We need to learn about what is important ... PPE stocks need to be maintained, investment into care and NHS systems continued. A pay scale which represents the role, not one that represents the interest society wishes to pay to a hidden industry.”

Message 1: Supported living settings need clear, timely guidance!

Clear guidance for those with a learning disability and/or autism living on their own or in a shared home with support (known as Supported Living) is urgently required in order for people to be supported out of lockdown and in preparation for a possible second wave.

As journalist Saba Salman explains: “The government’s guidance on coronavirus for supported living settings has been “under development” since mid-May, in contrast to care homes guidance, published three months ago and already updated at least once.” ([Whilst everyone else emerges from Lockdown](#) The Independent, 14th July 2020)

Easy Read information must also be published alongside any public announcements giving guidelines. These must be made available in a central place. People with learning disabilities/autism watch the news too!

Message 2: Coronavirus tests must be available in supported living settings

Coronavirus tests must be easily available for all those living and working in supported living settings.

Message 3: Support each person out of lockdown in the way that is right for them

Carefully consider how each person comes out of lockdown must (with each person and those important to them). This must be done in a way that keeps each person as safe as possible but also in a way that maximises their independence, autonomy, understanding and freedom. There is no 'one size fits all' way of achieving this. Commissioners must work alongside providers to ensure the necessary resources are available.

Message 4: Recognise and support the essential role of Support Workers at this time!

Agree how you will ensure Support Workers are able to recover and rebuild their energy – particularly considering a potential second wave may occur. This should include various forms of enhanced conditions such as additional leave, and/or hazard or bonus pay. It is also important to consider supporting people with their emotional well-being, offering reflective supervision and time with peers for informal connections and support.

Message 5: Recognise and support the role of families and unpaid carers

Ensure that plans are in place to support families (many of whom have been caring full-time for their loved ones due to reductions in support during lockdown). This support for families must be ongoing but needs additional consideration and action as we ease out of lockdown. Many families will need respite, support plans and resources in place as we prepare for a potential second wave.

Message 6: Society needs to act responsibly as lockdown eases

One of the most common messages from Support Workers was for the rest of society to adhere to guidance and respect the social distancing rules.



“...Please don't take for granted that things are improving and relax the standards that have helped get to this point. There are still so many people who are vulnerable and now is not the time to get lazy or they could suffer further.”

Message 7: Keep building on the community spirit

We must nurture the spontaneous and genuine natural connections with families, friends and the wider community that have been created during this time. They are key to ensuring that people are valued citizens in their community.

Message 8: Get ready for a possible second wave

Government, regulators, commissioners, and organisations/employers must:

- stock up on PPE.
- ensure that contingency and crisis plans are co-produced with self-advocates, families and Support Workers and communicated clearly.
- make sure clear policies and procedures for staff are in place, communicated and understood, fund/develop necessary training (including leadership training), reflective supervision and facilitate opportunities for peer support for Support Workers.
- establish relationships with local businesses such as supermarkets to ensure that priority food slots can be given to all those who receive support (not just those living in residential care homes).

Moving forward

A plea: support and grow the good work, the passion and determination that already exists in Social Care. Make this the expectation and experience across the UK.



“We have an opportunity for serious social change, so decide on what society should mean and aim to achieve it.”

Must have

1: Value and invest in Social Care

It's a mindset - don't undervalue Social Care or see it as the poor relation to the NHS. Millions of citizens in the UK need support to live their lives. As one Support Worker sharply observed.



“Support social care. You may not need it now, but the day will come when you or somebody you love will. The health of a nation can be measured by its level of support offered to ... [those in need]. Let's be the best we can be..”

With such severe cuts to funding for over a decade, Social Care is on its knees. Many families who are supporting their loved ones are also exhausted. At its worst, Social Care has become little more than a threadbare safety net. People are finding work-arounds to provide good support.

“In all kinds of ways, we have a system that doesn't work, that doesn't look after the people who need it well, that doesn't look after the people providing the care well.” ([Sir Andrew Dilnot. PoliticsHome.com 14th July 2020](#)). The incredible response we have seen during the pandemic is simply not sustainable unless more investment is made.

Must have

2: Ensure people have a place to live which really means ‘home’ - as you and we experience our homes

Governments (working alongside regulators) must value the fundamental differences between care homes, residential care homes and supported living. The more choice and autonomy people have the better! We must all commit to ensuring a future where people with a learning disability and/or autism, are supported to live in small shared houses or on their own, rather than in large residential settings. This pandemic has highlighted that people are safer when they live in their own home or share their home with just a few other people of their choice (with a consistent supporting team).

Must have

3: Support people to regain and experience flourishing lives*

At a time when many people with a learning disability and/or autism have had to ‘pause’ aspects of their lives, Support Workers are aware that some people may need focused support to regain these skills that are essential for their independence. Fundamental things like being able to shop, cook, meet up with friends and travel independently, create possibilities and a sense of pride of self and value in life.

We must commit to people moving forward as equal citizens. *‘If we do not stay strong, questioning and determined to do this, people will be denied their human rights. It is a dangerously slippery slope.’* (Warren, S. Giles, J. *A Practical Guide to the Reach Standards*, 2019)



“Having to work remotely at very short notice and never having done this before, it would have been great to get some more guidance on software packages instead of just being thrown in at the deep end - 9 weeks in and I am still learning how they work. I have been left feeling very inadequate in terms of my knowledge - there was an assumption everyone knew all about these things already.”

Bridging the translation gap between learning disability policy and practice in search of flourishing lives. NIHR School for Social Care Research. (PI) Dr Sara Ryan (Current research project).

Must have 4: Increase the pay of Support Workers!

The pay of Support Workers must increase to reflect their highly skilled, complex and diverse roles. Lack of Local Authority funding has driven down salaries, to the point where other sectors out-compete social care as a career choice when looking at pay alone. Social Care is fundamentally about relationships, trust, spending time alongside people, being motivated and making a difference – Support Workers must be recognised and rewarded as principle, key workers. A national Support Worker scale which pays people a salary which reflects their training and expertise is needed, now.



“[we’ll] look back and see the response of front-line workers stepping up and doing what they always do... this should be recognised and acknowledged.”

Must have 5: Harness that natural creativity!

Regulators and organisations need to work with Support Workers to minimise the restrictions that limit creativity. During lockdown many Support Workers reconnected with the soul of their work – to be in relationships with individuals and figure out together how to make the best of life. This creativity must continue.



“We should remember that we CAN DO things differently and we should continue to be as creative as we are being now.”

Must have 6: Lift the voice of Support Workers

Shout it from the roof tops – the profile of Support Workers must be understood and broadcast across society to ensure that their role is seen and valued. This must include Support Workers being fully involved in shaping support and services (alongside families, self-advocates and management).



“It has taken a pandemic for the general public to realise the contribution we are making on a daily basis, caring for vulnerable adults. before during and after the pandemic. It’s a privilege to work in health and social care.”

Thank you Support Workers...

- **Be proud** of your role and what you have achieved.
- **Look after yourselves**...let people know what you need to stay healthy and well.
- **Use your voice**. Share your insights, creativity and ideas with your colleagues, managers and peers around the country and beyond.

Paradigm
Pushing boundaries

