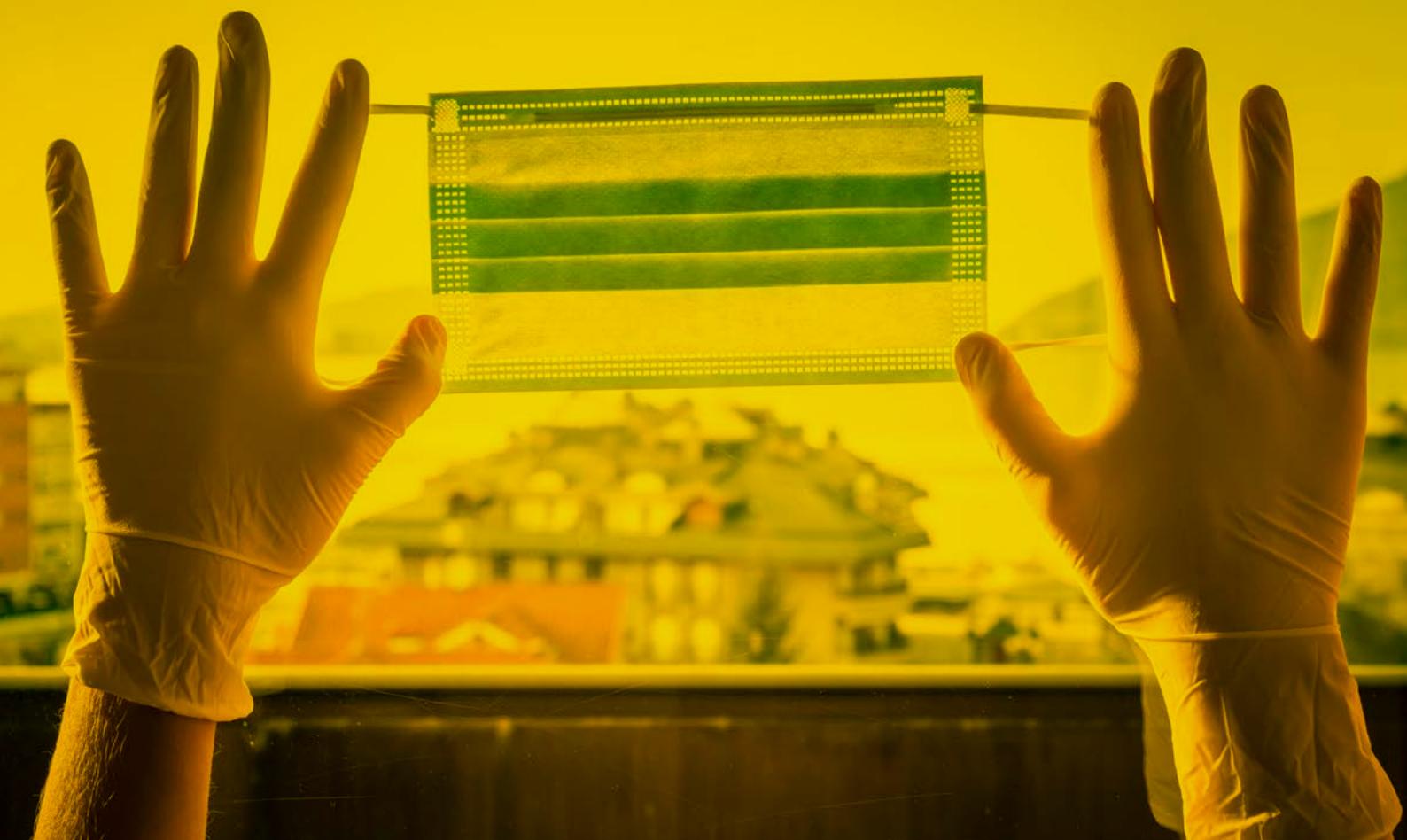




BUILDING PERSONAL POWER

**Key findings and proposals
from the Be-Human Register**





Building Personal Power

Key findings and proposals from
the Be-Human Register



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Emsée Fairbairn Foundation.

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Our sincere thanks go to the people who have shared their experience
of health and social care support during the COVID – 19 Pandemic.

Foreword by Baroness Jane Campbell

I am delighted to welcome and support this important report. Those of us who have worked and campaigned for independent living long ago recognised that personal power and control is key to people directing their own lives. Together disabled people and those who have long term health conditions have set out to build our personal and collective power. This is an essential part of our political struggle for rights and resources.



As this report demonstrates, building people's power is a challenging process for professionals in the care and support field. The examples and stories shared here reveal rather challenges that have emerged from inflexible systems which struggle to see the individual person, their life and circumstances and respond inappropriately. However,

the evidence, examples and analysis point to strong solutions and the real opportunity to support a “win-win-win” outcome. The ideas and recommendations show how it is possible to support people to achieve solutions that are right for them, while making better use of public service resources and allowing professionals to use their skills most effectively and rewardingly.

To achieve this requires action to support people to find their own solutions and to remove barriers along the way. It is also necessary to allow professionals sufficient flexibility and autonomy to enable them to confidently act as partners in supporting self-direction. Action in these areas will go a long way but will need to be supplemented by local independent support by Disabled People’s User Led Organisations and other similar models of peer support. By using this method disabled people and families will become the authors of their own independent living journey. In addition, this report also recommends, investment in a national network of groups and organisations to add in key additional assistance in some areas of information, advice, coproduction and mediation. Short term, the proposal to build on the current RACA initiative over the next period of COVID-19 and recovery from the pandemic is vital. This will allow both further practical support to people who have struggled in 2020 and underpin medium term ideas and proposals that can build the win-win for the future. I thoroughly indorse this report’s findings and recommendations.

Introduction

The Be-Human partnership of organisations has been supported by the Esmée Fairbairn Foundation, to record experiences and offer advice and support to people affected by COVID-19 from very early on in the pandemic outbreak. The key elements of recording were described as: register, advice, conciliation, arbitration (RACA).

This short report and its detailed appendix aims to tell the story of the people who registered their experience and the kinds of advice and assistance that, for some, made a difference. The report also aims to identify forms of practical assistance that could be further developed to the benefit of both the people using public services and the people offering those supports. Its core theme is power. Many of the people who registered their experience faced challenges that were sometimes caused, sometimes exacerbated by limitations on their personal power (limits formed from information and knowledge gaps). In those cases, a range of ways of supporting people to grow their power were critical, on a continuum of “supported to do it yourself” to formal mediation or legal intervention.

The challenges related were in some cases very specific to the COVID-19 context, but in many they might be seen as exacerbations of issues and barriers faced pre-COVID-19 that will be relevant post COVID-19.

A key reflection of those offering support was that “just enough of the right kind of support at the right time”, could make a very significant difference, in the interests of both people and practitioners/local systems. Focussing support in this way was far better than at a later stage when relationship damage had taken place and more expensive formal mediation or legal processes became necessary.

Context – the Be-Human Movement

The *Be-Human Movement* has been formed by people and organisations connected to *In Control Partnerships*. It's a group of people who see the challenges faced in today's society where people, due to a lack of personal power, are often not seen for the individual human beings they are in their interactions with public services.

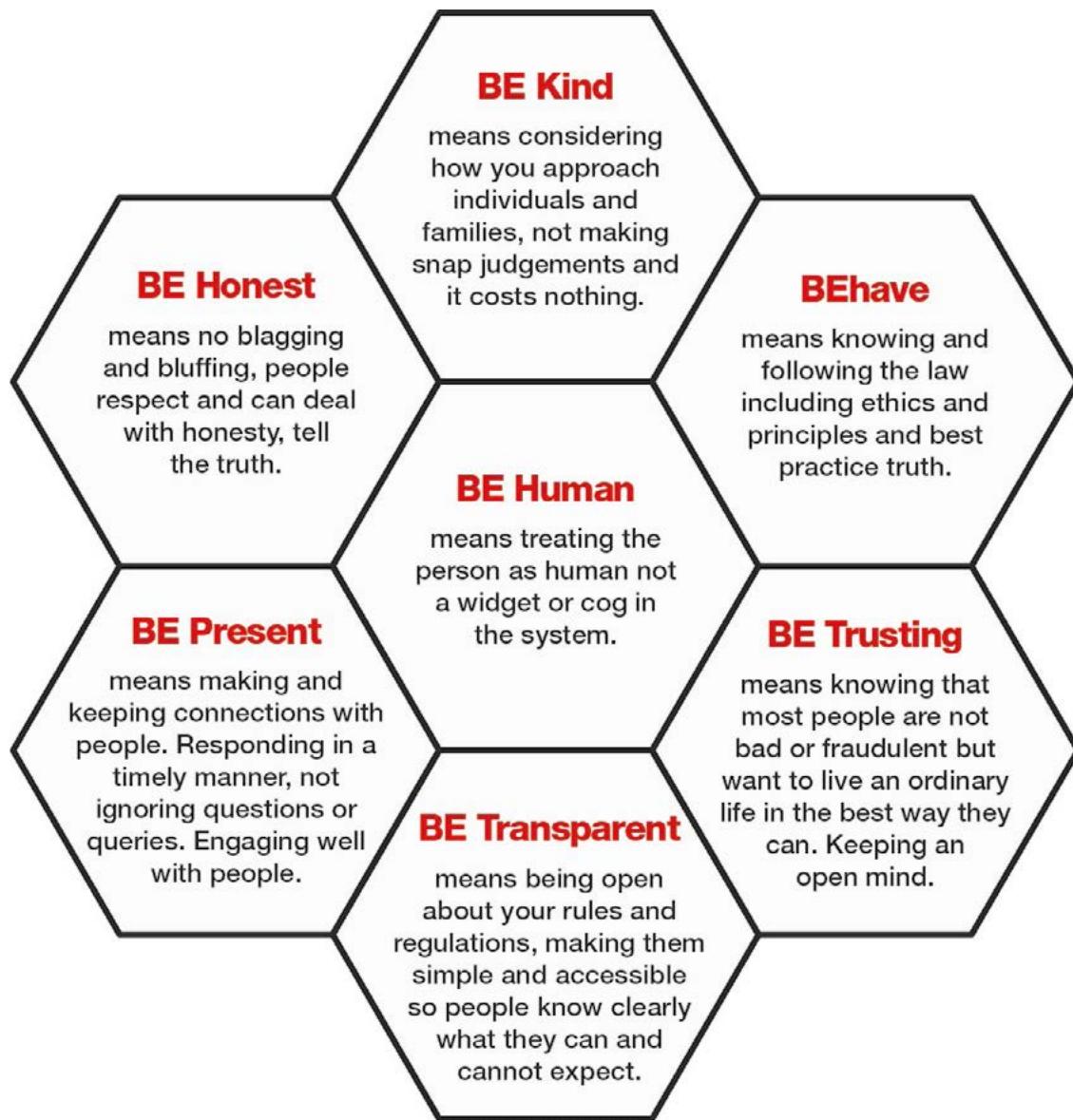
Despite the commitment and values held by individual professionals and workers, people are often effectively treated as less than the individual human beings that they are. We've all had the experience of being treated like a "cog in a machine" via automated responses, unfeeling customer service, institutions with impenetrable rules and regulations, confusing systems and bureaucracy, the 'computer says no' mentality.

This impersonal, effectively inhumane, treatment of people doesn't just happen in big institutions but takes place at many levels in ordinary everyday places and interactions. As well as the unhappy consequences for the people experiencing this treatment, these practices cause waste and inefficiency in a wide range of ways. Industrialised public service systems and the treating of people as commodities is bad for society.

On top of the 'normal' barriers to getting support for daily living, we are constantly confronted with inaccessible systems – "being sent down rabbit holes". We experience delays and associated worry, the stress of not understanding things, lack of opportunity to speak to someone directly and the overwhelming complexity of it all. The cumulative effect is extremely damaging to health and well-being, certainly to anyone who is disabled, older, or has a long-term health condition.

With added pressures on families, alongside reductions in support from public services in recent years, we believe it is everyone's responsibility to look out for each other and help where we can. We have therefore established a movement to positively encourage a better approach and foster flexible and supportive attitudes in all organisations – public, private, commercial and voluntary. We fundamentally believe people would rather help than hinder others but that often complex fragmented systems can get in the way of this. So by proposing some key principles we aim to help people in organisations take a good look at what they are doing, how they are doing it and talk about how they could improve things based on these principles.

The principles were created by a large group of citizens across the UK who had experience (direct or through research) into what made organisations feel more humane to those working or receiving goods or services from them.



All the work done in RACA is based on these Be-Human partnership principles; the NHS values of: working together for patients, respect and dignity, commitment to quality of care, compassion, improving lives, everyone counts; and the ethical framework for adult social care: *Respect, Reasonableness, Minimising harm, Inclusiveness, Accountability, Flexibility, Proportionality, Community*. (<https://www.gov.uk/government/publications/covid-19-ethical-framework-for-adult-social-care/responding-to-covid-19-the-ethical-framework-for-adult-social-care>)

These principles both inspire and underpin the *Be-Human* register initiative – the why and the what of the work that we have done.

Who did what, why and how?

The formal objectives of the initiative were:

To record experiences of health and social care support during the COVID – 19 pandemic and beyond

To identify what went well and what not so well

Where appropriate and practical to intervene and help to improve experiences

To learn from experiences and develop best practice

To inform future strategy particularly plans for future similar episodes

For the *Be-Human* partners it was very important to go beyond analysis and reporting with policy recommendations. They were clear at the outset of their intention to act as well as listen, where people wanted this.

A register for people to record experience and optionally to request assistance was set up and publicised widely across the partners' networks. At the time of this publication 495 people shared their experience and 209 people requested advice and support which was provided by members of the partnership with appropriate experience and skills. The initial 445 experiences shared and 48 direct advise examples were analysed by Professor Chris Hatton and these are categorised and summarised in the report appendix. The partners involved in providing support reviewed and reflected on their activity and outcomes in order to generate recommendations and advice to public agencies supporting people during COVID-19 and beyond.

Detail of the issues and experiences registered is provided in appendix 1.

People were invited to share experiences relating to:

- Experiences/decisions relating to adult social care or NHS associated teams
- Information or experiences concerning easements or changes to support
- Decisions or experiences pertaining to access to treatment
- Decisions or experiences of personal budget or personal health budget holders who micro commission their own provision

Key areas emerging from the register related to:

Care and support, and other aspects of support to help people live independently

- Positive experiences, good communication and flexible support
- Poor communication
- Health services stopping during COVID-19
- Care and support stopping during COVID-19
- Education stopping during COVID-19
- Cuts to support
- Services not providing reasonable adjustments/flexibility
- Care homes
- Services preventing people from going out or meeting family
- Shielding, self-isolation and the support being offered putting people at risk
- Paying for support
- Help to get food/shopping or prescriptions
- No assessment or future planning
- Back-up planning

Direct payments

- Flexibility
- Accessing personal protective equipment (PPE)
- Personal assistants (PA)
- Contact from the council or Clinical Commissioning Group (CCG)
- Testing and treatment for COVID-19

Advice and assistance

The people who asked for assistance linked to the issues registered needed this to be provided in a range of ways linked to the issue and their local and personal context. The forms of assistance can be categorised as:



Underpinning levels 1-3 The Be-Human partners provided some forms of information and tactical advice via webinars and materials:

The series of webinars offered by people with lived experience and specialist expertise in areas emerging from the register or anticipated by partners:

- Employment issues for people on direct payments
- Accessing care during the coronavirus crisis
- Contingency planning during the coronavirus crisis for people on direct payments
- Let's talk about...employing personal assistants
- Benefits and welfare system changes during COVID-19
- Housing in the UK during the coronavirus crisis
- Staying healthy at home during the coronavirus crisis
- Let's talk about...when the heart stops beating – a frank and fearless conversation about CPR
- Planning ahead for decision making (power of attorney)
- The Court of Protection and Deputyship.

1. Do it Yourself.

Where people effectively know what they need and can access it themselves from the on-line resources of the Be-Human partnership or other sources such as government or government agencies like NHS England. People then feel confident to represent themselves in engagement with public agency practitioners or managers.

2. Supported Do it Yourself.

Where people might know they need something but are not sure what, need to be listened to and then signposted to relevant information and advice which they can then use to represent themselves.

3. Tactical Advice.

This was where people were wanting help to make a persuasive case effectively to public agencies in order to get the best outcomes. It could include, for example, wording and structuring communications and making effective use of guidance relevant to specific situations.

4. Informal consolidation or mediation support.

People wanting tactical advice and assistance as above but also support to take this forward or mediate the situation with public services to avoid dispute.

5. Formal consolidation or mediation support.

This usually happened when people were already in dispute with public service bodies or where a request came through from such a body for formal support from a trusted independent body.

6. Formal complaint/legal challenge.

This might be through local complaints procedures to a statutory body such as Ofsted or CQC etc. If through a legal route this might be via a solicitor or the Local Government Ombudsman.



***“When the heart stops beating:
a frank and fearless
conversation about CPR”***

Thursday 16th July 2020 2.30pm



**Practical tips on contingency plans
during COVID-19
for people on Direct Payments**

Wednesday 26th March 2020 11am

A Facebook group and access to web-based advice materials including a collated series of advice materials from trusted sources plus links to relevant government advice materials.

The templates and examples developed included:

- Life directives (?)
- Emergency planning template
- NHS best practice template
- Template Local Authority letters

Where “face to face” online or phone assistance was required these were logged and categorised then initial screening of the request was used to direct an appropriate person from within the partners to offer help.

Examples of requests for advice and responses

Simple requests and responses

Some people struggle with finding guidance and searching for specific things even if they have heard about them via Facebook etc. This may be because they are too busy, too stressed or simply do not know.

They need someone:

- who knows what guidance they need after having a brief conversation or email exchange
- knows where to look for it to enable a direct link or to provide particular sections of the material that will help

It was notable that such requests were as likely to come in from professionals supporting people as much as families and individuals.

In both the Care Act and in various pieces of NHS guidance and protocols there are duties to make information more accessible. There is lots of good, helpful information available but if people cannot find it or relate the guidance to their situation it is effectively inaccessible. Most of these requests required a half hour or less phone call or an email exchange but these make a very big difference in enabling people then to “do it yourself”. So, there are key lessons about what is needed to bridge availability of information and its effective use.

Examples of people being supported to ‘do it themselves’:

REQUEST from a care home manager: “Can you send me the latest government visitors guidance”

RESPONSE E-mailed back direct link to Government Guidance

REQUEST from a Disabled People’s User Led Organisation: “Are the rules different now for direct payments? Someone said that there was specific COVID-19 guidance”

RESPONSE Talked over phone then followed by texting the link to the guidance.

REQUEST from a Personal Health Budget user: “I have a Personal Health Budget, how do my PA’s prove they are keyworkers”?

RESPONSE By phone explained how and where this is happening well, linked to specific points in Guidance.

Some people needed support with tactics via on-line or direct conversation

Examples of people supported with tactics or informal support:

REQUEST Karl had his direct payment stopped during COVID-19. He was informed that as he used it for activity that was not possible during the pandemic, he could not spend anything from his DP account. Karl was unable to get legal aid and was extremely anxious.

RESPONSE We supported Karl on-line to develop a contingency plan which highlighted how his needs would be met differently during COVID-19 and how the DP would be utilised to continue to meet his needs. We then supported him to get the new interim plan agreed by the council.

This was a case of “computer says no” – a lack of flexibility or consideration. Karl, who has autism was upset and angry as his reading of the Guidance said that flexibility was possible. So the support was to help him present the facts differently and the council to respond appropriately.

REQUEST: Jenny had been told she was due to be assessed for Continuing Health Care (CHC) but was struggling to understand the DST (Decision Support Tool) domains and how, if eligible, this would shift from social care direct payments to Personal Health Budget arrangements. The Clinical Commissioning Group had told her they would provide an agency and she wouldn’t need her current personal assistants.

RESPONSE We went through the process and how it works with Jenny. We then helped her to draft an email to the CHC team stating that if she was found to be eligible, she would want to retain her PA’s via a Personal Health Budget for support rather than a commissioned agency. We also had discussion with CHC nurse to go through the same process and how it would work from a CHC/CCG point of view.

This was a situation where Jenny needed more understanding of the CHC system and the professional involved information and support to put a more personally designed approach in place – leading to the right result for Jenny and a good outcome from the professional’s perspective – a win-win, with the prospect of further good outcomes for others.

In some cases, more significant research and mediation was needed.

Examples of people supported with formal mediation or legal challenge

REQUEST: John is receiving palliative care and is supported solely by his wife Betty with district nurse support once a fortnight and a MacMillan nurse contact. They needed some specific equipment but had not been able to get agreement for the equipment to be referred for and prescribed. Betty had contacted her MP and local solicitor to challenge the decision to reject but felt she didn’t want to expend energy in this way in what could be the last months of John’s life.

RESPONSE: This situation was raised with the NHS Trust, equipment commissioners and CCG. We supported an exploration as to at what point in the system this process had gone wrong and why and what could now be done. Following the successful resolution of the specific situation a system review is taking place.

This situation threw up issues relating to correct professional practice in following through specific process and more systemic issues. The exploration found caring and hard-working individual professionals struggling to achieve the optimal response to their patient. Each professional was performing a specific role but it was difficult to bring the situation together holistically without advocacy and exploration that brought the system together to achieve the right result for the Trust’s patient and efficient use of Trust resources. Because the system operated in this fragmented way the patient and their family had very little power to influence their situation as they could only engage with each specific process and with professionals needing to pass decisions upwards.

REQUEST: Peter’s mum manages his direct payment, one of his PA’s is due off on maternity leave and the family were concerned about trying to recruit and introduce new staff into his home during the pandemic, therefore wanted his mum to become a paid PA on a temporary basis until he could recruit. The Council, however, were concerned that as his mum managed the direct payment there would be a conflict of interest.

RESPONSE: We worked and had discussions with both the Council and family to establish Peter's capacity in understanding the decision, trust, transparency and adding some simple measures to ensure that Peter had a route to raise any issues. This was a situation where a direct payment had been managed for ten years without problems but council officers found it difficult to work through capacity and safeguarding issues initially. The intervention involved detailed talking through of the situation with the social worker, their manager and then the team manager of the funding panel to get it agreed. A proposal for practical resolution was eventually agreed to the satisfaction of the family and council officers. Essentially the intervention was that of critical friend role to the Council and supporting the family, in their frustration and anxiety and hence finding a solution without legal intervention or complaint. Key to successful resolution was a "what's the worst that can happen if we take each course of action" conversation.

In each of these situations, operating at different levels of interventions there were some common experiences and lessons:

- Gain a better understanding of wider context leading to "win-win" results - identifying blocks in the system that are not in patients/ persons best interests or that of the professionals or system.
- The vital importance of seeing the person as a whole and in their context.
- The need to then achieve a whole system response rather than be limited to responses from single elements and processes.

By doing these things, with support in the more complex or conflicted situations, the people and key professionals involved were able to find solutions which:

- Avoided further action to pursue resolution
- Built better relationship and communications
- Took lessons from individual solutions to build strategic shifts in system and practice

Important issues and recommendations

The *Be-Human partners* offering this support reflected that activity at the levels of 2-4 were usually in the best interests of both people and families using public services and the services themselves. They could offer early and less expensive ways of resolving issues which could reduce ongoing relationship and communication challenges that were often practically hard and emotionally draining for people and could lead to long term problems from them, the professionals and agencies they were engaging with.

The partners identified important gaps in local capacity and functions meaning 2-4 level activities were not happening often enough. It became clear that though local advocacy organisations offered an important function in ensuring people's voices were heard, they were often limited in their ability to provide independent representation and sometimes specialist advice, especially beyond level 3 but even sometimes at level 2. The Be-Human partners concluded that it would be in the interests of both people/ families and public service practitioners and agencies for there to be supplementary/ supportive access to some support in this space, provided in a cost-effective way. Some possible approaches are suggested in the following recommendations:

Short term it is important that the current project be extended to April 2021 in order to:

- Continuing to provide a platform for a second phase of information and advice support from the national network via helplines, webinars etc.
- Support further local practical intervention and mediation during the current phase of the pandemic.
- In particular, to respond to new types of support requests or those becoming more pressing linked to the current stage. For example, we are seeing issues arising or becoming more acute linked to:
 - Burnout for family carers and staff
 - Mental health issues
 - Challenges linked to staff sickness and service cancellations
 - Insurance
- We anticipate many requests linked to the vaccination programme and expect to need to provide information via collective and individual means.
- Further record experiences, including those relevant to emergence

from the pandemic, in order to advise national and local public service organisations for the “recovery phase”. This would include providing key intelligence to inform DHSC and NHS England guidance as well as support initiatives advising local public services including the Think Local Act Personal led Insight Group.

“



“When we set up the register, it was our intention to establish a safe trusted place where disabled people & those with long term health conditions and their families could record their experiences and seek support and advice. We are grateful for the funding from Esmée Fairbairn Foundation that has enabled this to happen. We believe it is critical in our learning from the momentous health events of 2020 that all voices are heard, including the voices of us disabled people and our families. At the beginning of the pandemic we saw plenty of evidence that our voices were not being heard including drawing up a ‘frailty’ scorecard to ration treatment and the issuing of blanket DNACR notices. Some of these experiences are reflected in this report. As time has progressed, and we have all learnt more about the consequences of this pandemic, understanding and access to vital equipment has improved. But perhaps not far enough yet which why I hope health and social care professionals will read this report with interest. One of the frequently mentioned experiences is poor communication. Of course responding to a pandemic the like of which no one has experienced before is not easy but no communication just makes a bad situation worse. Even if the answer is not known communication is essential in giving all people and their families the dignity and respect deserved, It is also clear that in emergency planning the understanding of how health, social care, and education needs of disabled people and those with long term health conditions are met in the community has been lacking. This must be improved in the future. There are 70,000 employers of some 135,000 personal assistants to meet care needs, a significant part of the health and social care landscape. <https://www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/publications/Topics/Individual-employers-and-personal-assistants.aspx>. Finally it has to be said that someone who’s life is threatened from Covid is no more or no less important than someone with a long-term health condition who’s life is threatened by not having access to vital services. These issues are complex but we must find a way of valuing all life equally”.

Sue Bott CBE

Building on RACA

A number of promising ways of using the project learning suggest themselves. Some will require additional resources, while others might be achieved via use of or alignment of existing capacity and programmes. It would be possible to bring key groups and organisations together to align their national contributions to local action to achieve the “win-win-win” described above:

- From the register and our interventions, we can develop more detailed understanding and ideas for system and practice adjustments for longer term improvement. These could be shared with key national and local public service players across health and social care via established information, development and support programmes. For example, the strong learning about direct payment flexibility and adaptions of process could be built into practice post COVID-19. Another example is the use of effective conversation and negotiation approaches in heading off or resolving potentially damaging and expensive situations while embedding personalised practice. A third is the positive impact of levels of professional autonomy in reducing the impact of organisational complexity.
- Based on the experiences registered, we could identify a range of national level best value forms of support that, added in to local infrastructure, would add value in achieving the “win-win-win” between people, professionals and systems and build a realistic model for how these elements might be organised and supported via a network. Subject to resources, a network could be piloted in 2021/2.
- Contribute to developing national health and social care policy with proposals around the local infrastructure needed to build personal power as set out in this report.
- Consider the establishment of a national mediation function, possibly linked to the proposed network, that could offer a kind of ACAS function that could mediate and provide supportive intervention to local people, professionals and systems in order to find productive solutions to complex and potentially conflictual situations and model solutions that could be taken from the individual to the systemic level in local public services.

Appendix



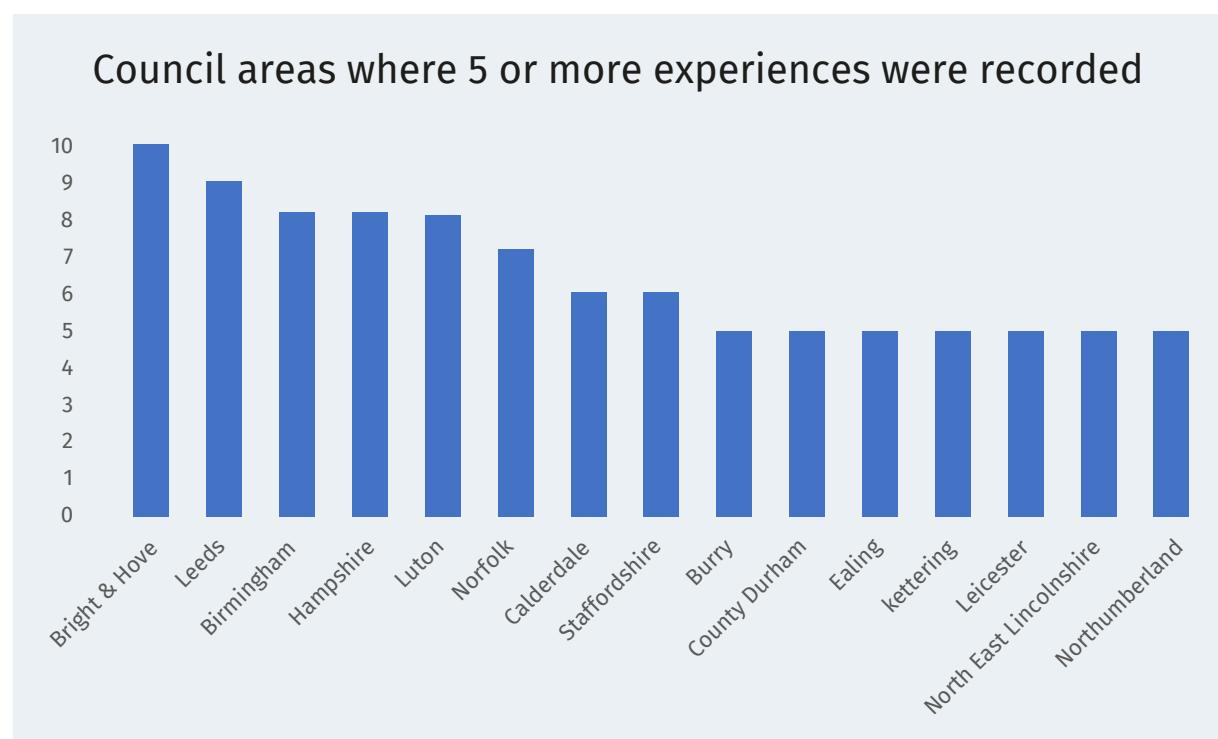


Appendix – experiences and interventions

Who recorded their experiences on the register?

From 12th May to 9th September 2020, 445 people recorded on the register their experiences or the experience of someone else (with the person's permission) in a form that could be analysed (174 entries were blank). Of the 445 registrations, 305 people were sharing their own experience (with a further 16 people getting help), and 106 people had permission to register someone else's experience on their behalf.

Council Areas



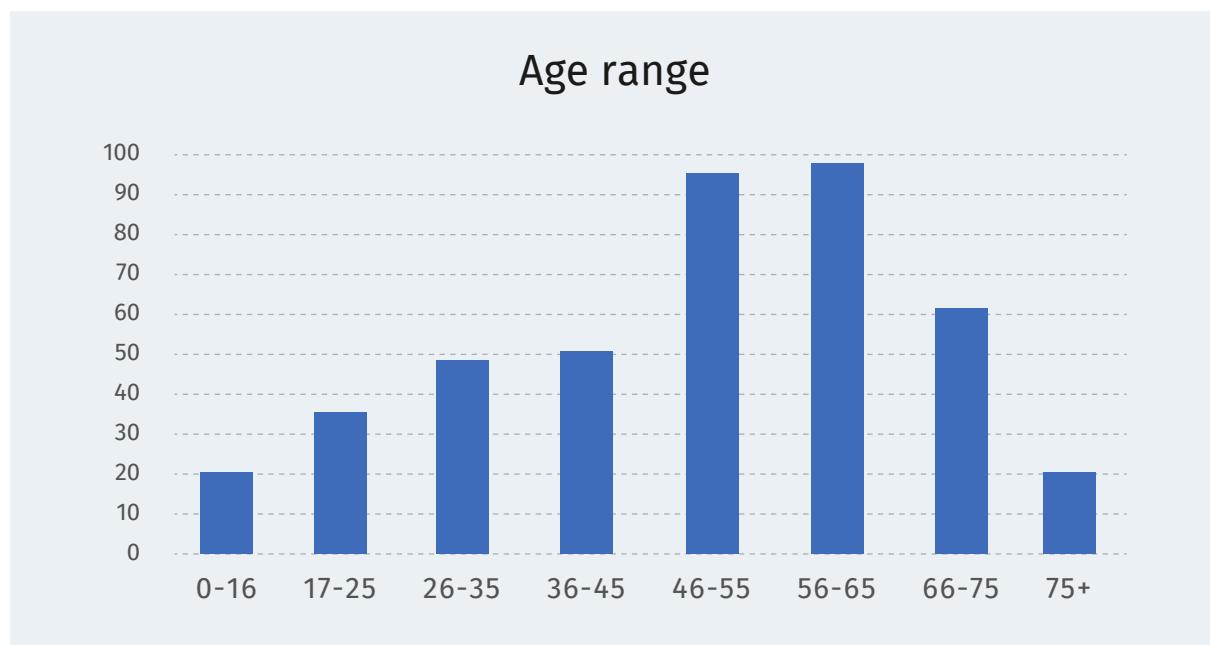
Overall, 250 experiences were registered in May, 151 in June, 35 in July, 5 in August and 4 in September.

On registrations up to 27th July, postcode look-up was used to find which council areas people's experiences were coming from. Out of a total of 343 possible different councils in England (including both county councils and district councils in 2-tier areas), experiences were registered from 169 different council areas in England, with registrations from a further 8 councils in Wales, 7 councils in Scotland and 4 councils in Northern Ireland. Council areas where 5 or more experiences were recorded were as follows:

10 registrations: Brighton & Hove	6 registrations: Calderdale; Staffordshire
9 registrations: Leeds	5 registrations: Bury; County Durham; Ealing; Kettering; Leicester; North East Lincolnshire; Northumberland
8 registrations: Birmingham; Hampshire; Luton	
7 registrations: Norfolk	

Age range

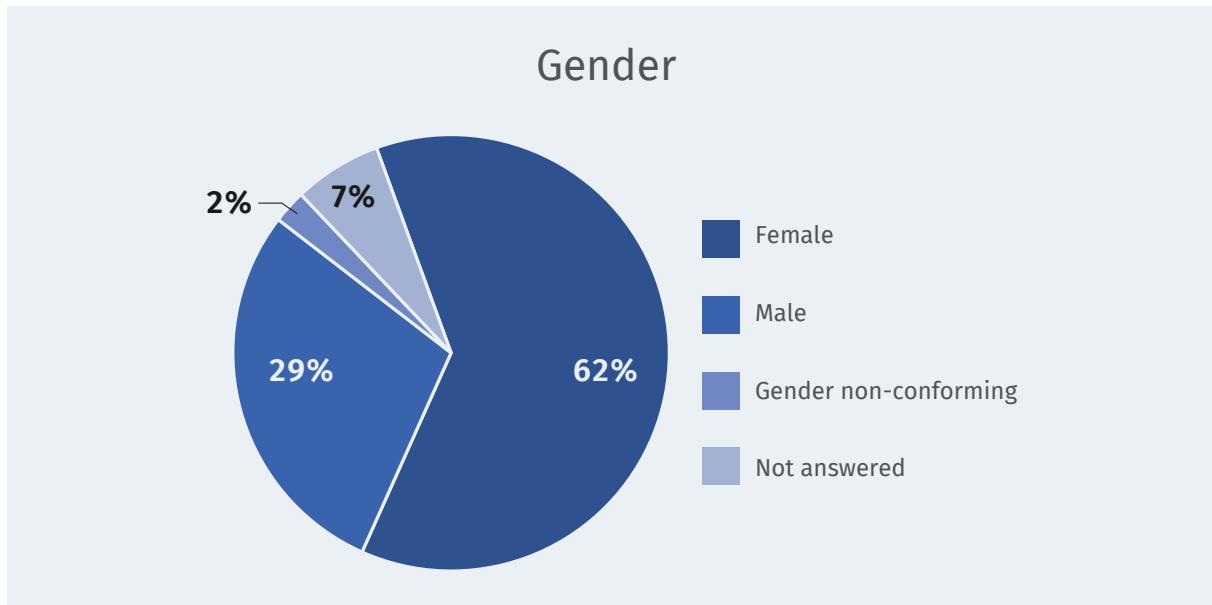
The ages of people whose experience was being registered (whether by themselves or by someone else on their behalf) covered a very wide range:



0-16 years	20 people	46-55 years	95 people
17-25 years	35 people	56-65 years	97 people
26-35 years	48 people	66-75 years	61 people
36-45 years	51 people	75+ years	20 people

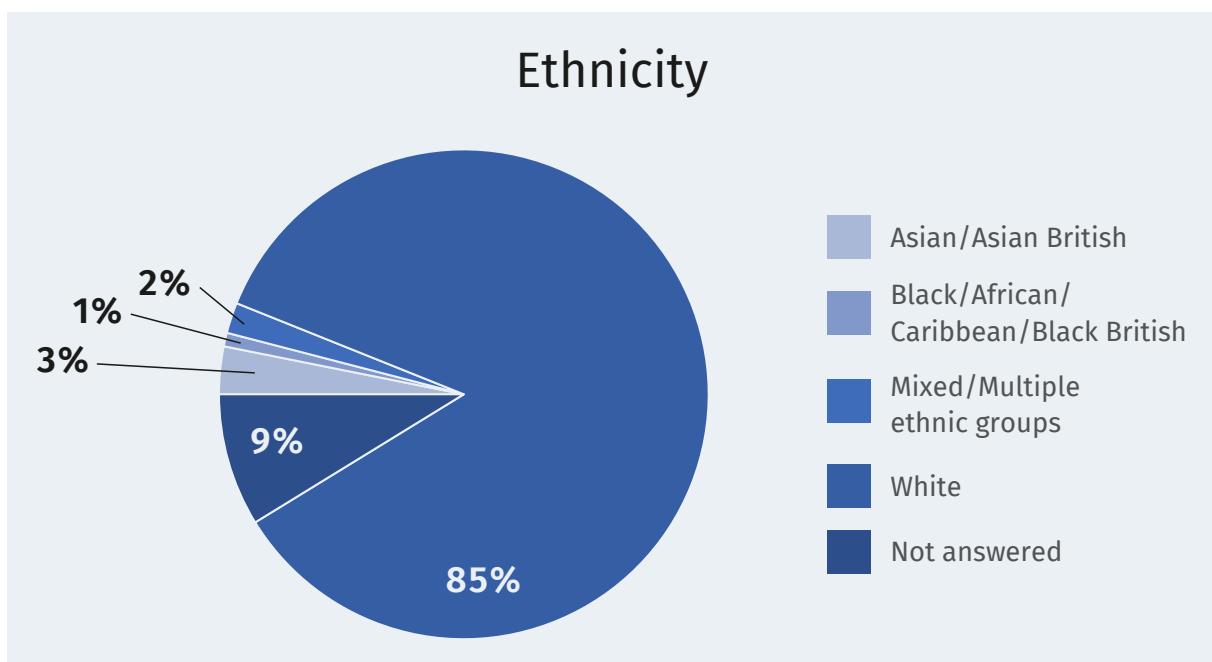
Gender

Out of the 445 people registering their experiences; 277 people (62%) reported a female gender, 128 people (29%) reported a male gender, and 11 people (2%) reported being gender non-conforming, non-binary, transgender or other in terms of gender.



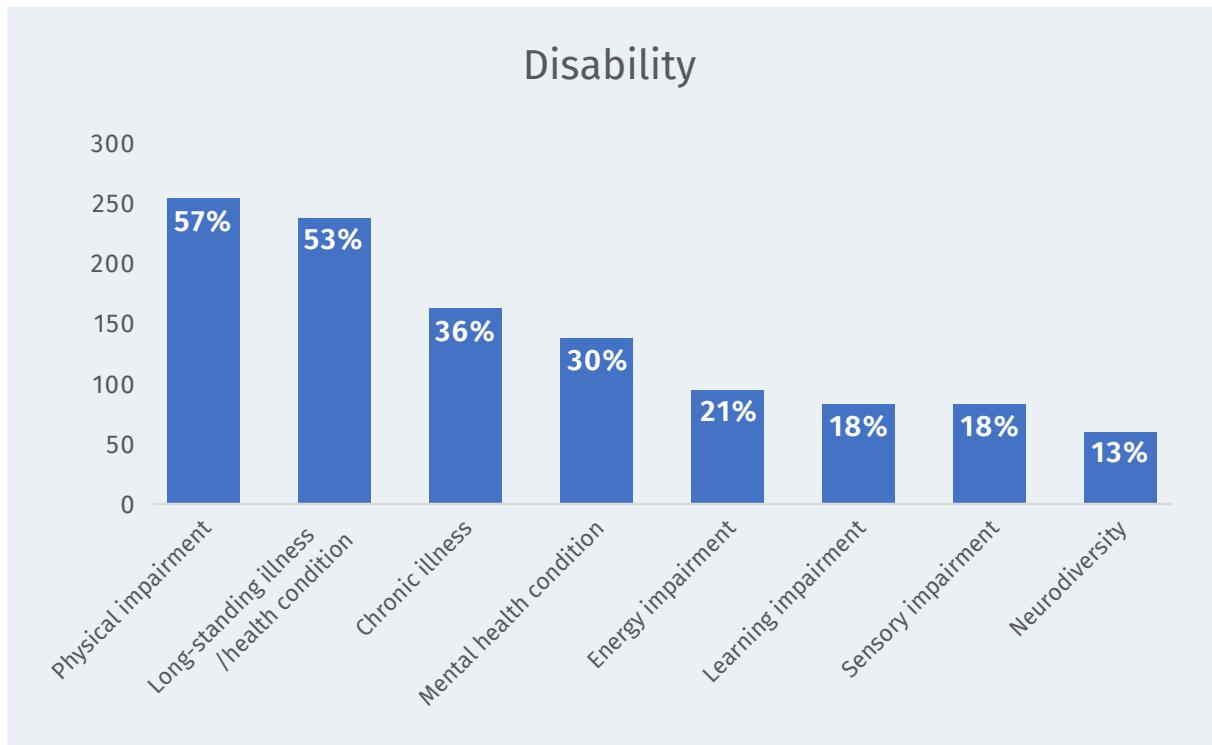
Ethnicity

In total 379 people (85%) described their ethnicity as White, 14 people (3%) as Asian/Asian British, 4 people (1%) as Black/African/Caribbean/Black British and 9 people (2%) as Mixed/multiple ethnic groups.



Disability

379 out of the 445 people registering their experiences (85%) considered themselves to be disabled.

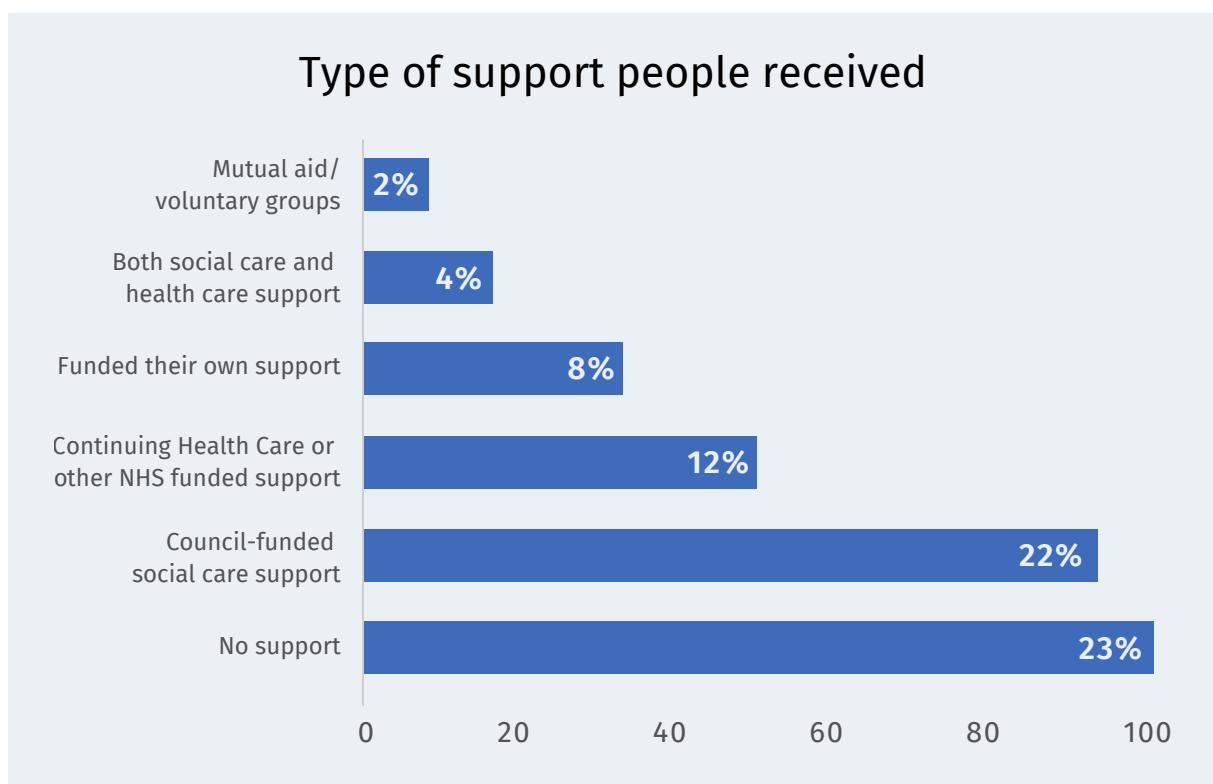


People could choose to be described in any, all or none of the following categories:

Physical impairment	252 people (57%)
Long-standing illness/health condition	235 people (53%)
Chronic illness	160 people (36%)
Mental health condition	135 people (30%)
Energy impairment	95 people (21%)
Learning impairment	82 people (18%)
Sensory impairment	82 people (18%)
Neurodiversity	60 people (13%)

Type of Support

People reported on the type of support they had been receiving. The most common responses were 'no support' (103 people; 23%) and council-funded social care support (96 people; 22%). In total 52 people (12%) reported getting CHC or other NHS-funded support, 35 people (8%) funded their own support, 18 people (4%) received both social care and health care support, and 10 people (2%) reported getting their support through mutual aid/voluntary groups during COVID-19.



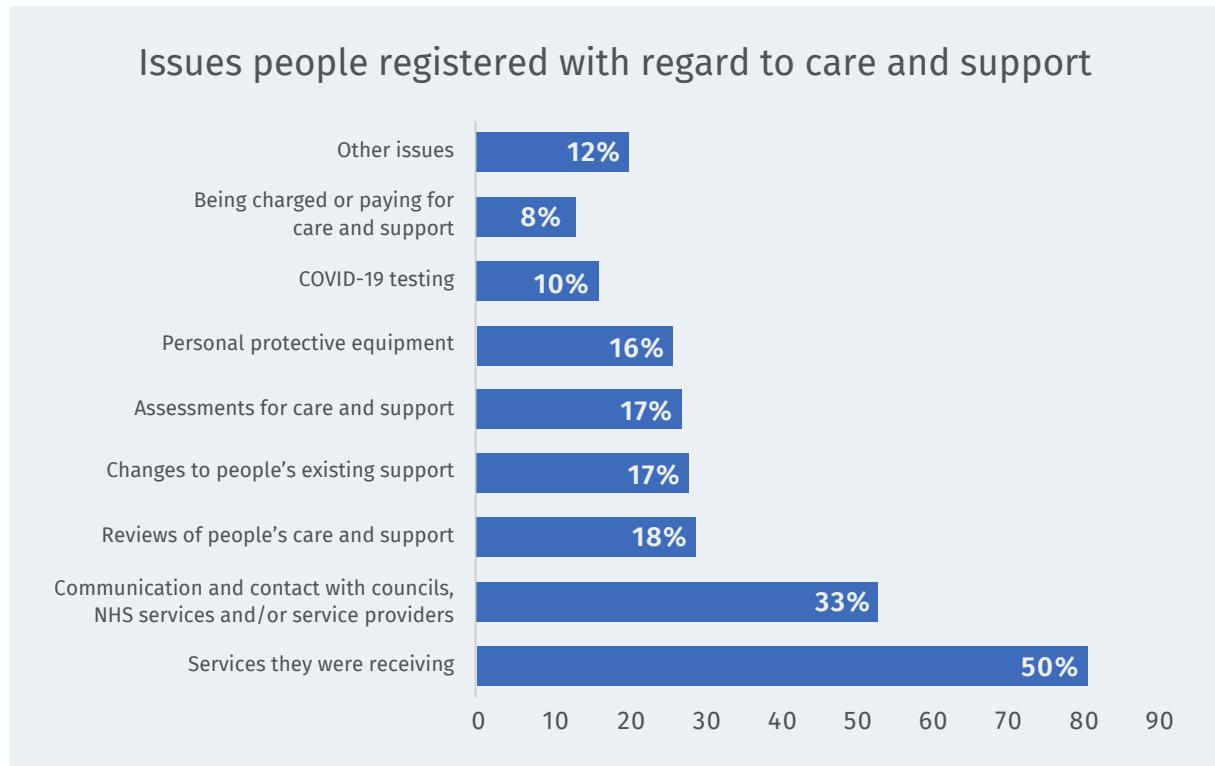
What did people want to record on the register?

People could report on the register about their experiences with regard to several aspects of how they were being supported through COVID-19. People most commonly wanted to report on their care and support (163 people; 37%) and other aspects of support to help them live independently (80 people; 18%), with another 40 people (9%) wanting to report on direct payments. Only 12 people (3%) wanted to report on their treatment for COVID-19.

Overall, 159 people (36%) reported that they had enough information about care or access to treatment during COVID-19 in accessible formats/community languages to meet their needs. Almost half of people (217 people; 49%) answered 'No' to this question, with 47 people (11%) saying the question was not applicable to them. People with sensory impairments (61% of people) were most likely to answer 'No' to this question.

Issues

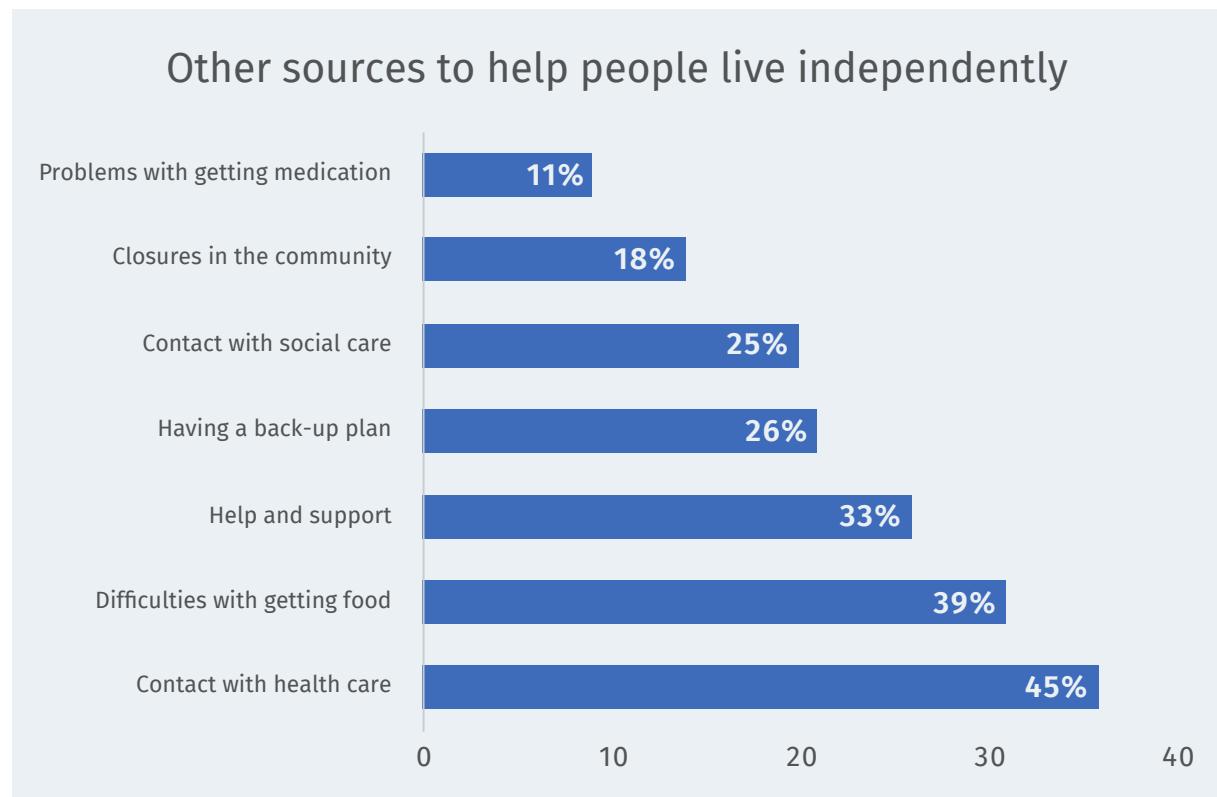
Care and support, and other aspects of support to help people live independently



The 163 people registering an experience about their care and support were asked about what aspect of their care and support they wanted to register (they could pick as many as they wished), what happened, and the reason for what had happened. With regard to care and support, people most commonly registered issues about:

Services they were receiving	81 people; 50% of those registering issues with care and support
Communication and contact with councils, NHS services and/or service providers	53 people; 33%
Reviews of people's care and support	29 people; 18%
Changes to people's existing support	28 people; 17%
Assessments for care and support	27 people; 17%
Personal protective equipment	26 people; 16%
COVID-19 testing	16 people; 10%
Being charged or paying for care & support	13 people; 8%
Other issues	20 people; 12%

Other issues

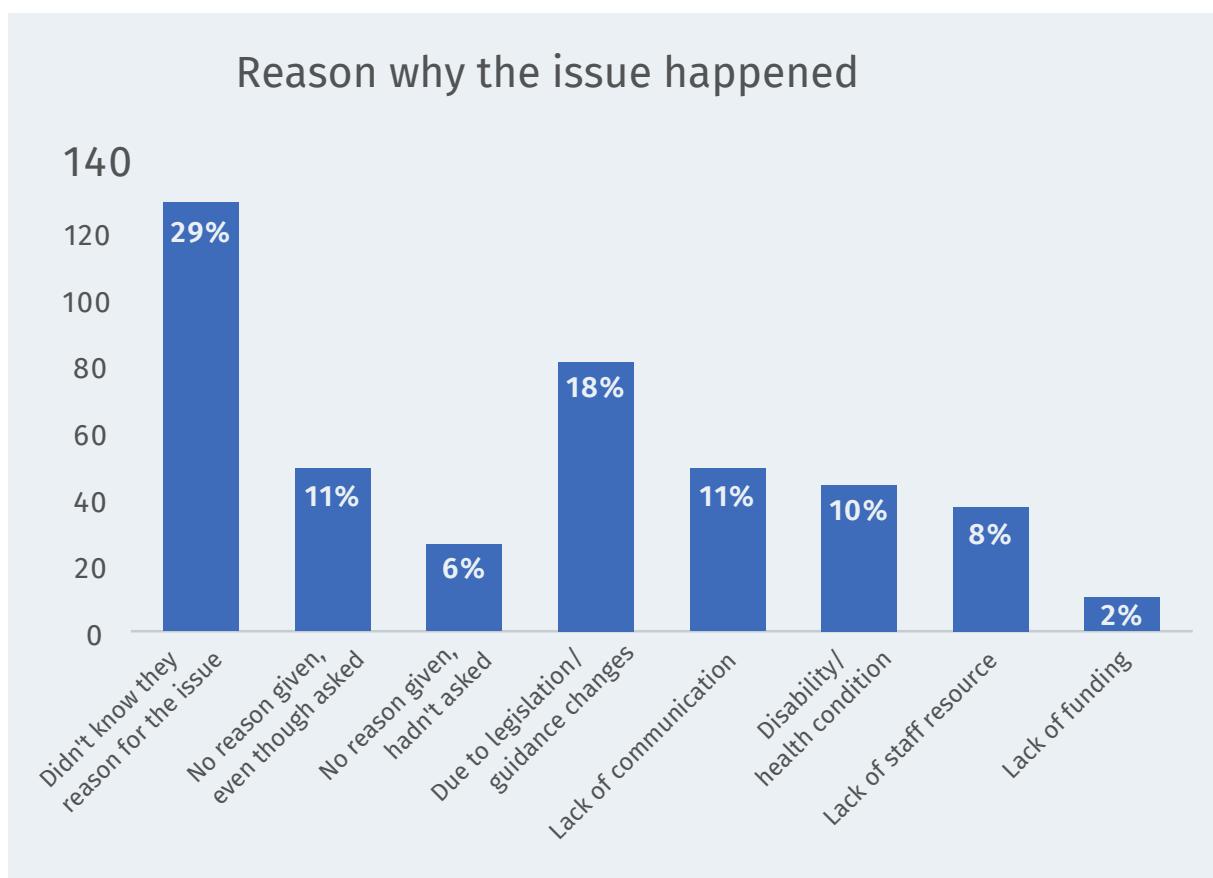


The 80 people registering an experience about aspects of support to help them live independently were asked about the issue they wanted to register. People most commonly registered issues about:

Contact with health care	36 people; 45% of those registering issues with support to help people live independently
Difficulties with getting food	31 people; 39%
Help and support	26 people; 33%
Having a back-up plan	21 people; 26%
Contact with social care	20 people; 25%
Closures in the community	14 people; 18%
Problems with getting medication	9 people; 11%

The reason why

Across all these specific issues, people most commonly reported that they didn't know the reason why the issue had happened (127 reports), with large numbers of reports that no reason was given even though the person asked (48 reports) or no reason was given and the person hadn't asked (25 reports). Reasons most commonly reported were guidance/legislation/changes in the law due to COVID-19 (80 reports), communication (or the lack of it) (48 reports), the person's disability or health condition (43 reports), a lack of staff resource (36 reports) or a lack of funding (9 reports).



Quotes

Many people wrote in about their specific situation, and all these statements were organised into themes. Where necessary, all quotes throughout this report have been edited and anonymised to ensure that individuals, the places they live and the services they are describing cannot be identified. A brief description of each theme with quotes from people completing the register follows.

Positive experiences, good communication and flexible support

A relatively small number of people mentioned positive experiences of support during COVID-19, including good communication and flexibility in how people were supported.



I haven't had a negative experience at all. My agency carers have worked as usual and the PA I employ independently is also my best friend and he's also worked as usual (although he's been bringing his young daughter for some visits, which hasn't been a problem)



Lump found in breast. GP has responded quickly with home visits and referral for urgent breast cancer screening.



After the first shock, front-line staff started to work out how to give us care we needed. I would say I am receiving 80% of the care I need, albeit in new and innovative ways. e.g. I needed a blood test, normally I have to arrange for an elderly relative to drive me to surgery (five miles away), and wait for up to 30 mins for nurse to be free. Now, I explain to my consultant that I don't like to ask for lift to surgery, so consultant himself phones surgery and gets the District Nurse to come to me, and in 10 mins take blood. Brilliant!



I am contacted weekly by the team who helped me get a job to find out if I am ok. They offer to do my shopping, pick up medicine and provide me with things like books, jigsaws, dvds and craft materials to stop me getting bored.

Poor communication

More common were experiences of poor or absent communication from a range of people and services.

“ I have found it impossible to locate someone with the CCG who can take my enquiries about keeping safe and supported during the pandemic. I have asked for PPE which has never been responded to, apart from a delivery of 10 masks and 6 aprons. No gloves or sanitiser. And that is that for the last 10 weeks. As I employ 6 PAs it is impossible to self isolate so some kind of protective equipment is very important. Nobody from the CCG has contacted me. I received a letter from my hospital consultant informing me that my specialised unit was now a covid ward, so I am afraid that if anything should happen to me, like my feeding tube needs changing, I will not have the specialised attention that I require.

“ Phone calls are never returned and we have given up trying

“ More stonewalling and ‘Sorry we can’t’ and ‘Oh hasn’t anyone been in touch?’ and ‘Well we haven’t the funding’ or ‘We don’t do that in this region’, blah, blah blah.

“ Nothing. Absolutely nothing. First off, a lady from the council was calling to ask if I needed anything. She went to the shop for me twice but I haven’t seen or heard from her since then (middle of April). I’ve called her but she hasn’t replied. Which makes me very reluctant to call her again. I was independent before getting ill, so I find it hard to beg for help.

Health services stopping during COVID-19

Many people reported regular or planned health assessments, treatment and support stopping or being delayed indefinitely during COVID-19.

“ The long term intensive treatment programme I was first meant to start in January, that was then put to March, has now been put on hold indefinitely and I have no updates on when I will now be able to start this. All in-person support, apart from depot injections for those who need them, has been stopped by the service until further notice.

“

My son needs his tooth removed and can't access any services due to Covid. Also any services or clubs to help him manage anxiety or stress. As social distancing been very hard for him.

“

The psychotherapy I was receiving up till Covid was stopped and the therapist redeployed to support front line staff. I had a mental health crisis just before lockdown and not having access to the therapy severely impacted on my mental health.

“

No monthly blood tests, that check if my liver is ok, due to the medication I take. I need to get my toe nails cut & I can't, this & less physical activity due to shielding, is making my ankles & feet worse.

“

My 3 monthly treatment for disabling vestibular migraine which enables me to manage the condition has stopped. I can barely stand up without falling over, I can't drive, I can't go into supermarkets and can't get deliveries because I can usually manage with my treatment. It makes me constantly exhausted and affects every area of my life.

Care and support stopping during COVID-19

Similarly to health services, many people reported care and support services completely stopping during COVID-19.

“

I am a student in another city but currently at home with my parents. My support package provides 24/7 when I am away from home and 49 hours a week when I am at home as my parents are expected to do most. My mother manages my DP and PHB on my behalf. At home at the moment I have no outside help at all. This is because: a) I should be at Uni so don't normally have any PAs at home at this time so there is no-one suitable trained and experienced; b) we are being very cautious about anyone else coming in and out of the house in the absence of testing. I have CP and whilst not in the shielding group, as I have dysphagia and dysphasia I am at much more risk of respiratory conditions. If my parents get ill then I would have no overall support as we have been told that CHC would never provide 24 hour cover while someone is at home.

“ I am staying with my parents because of lockdown and because I don't want to be in the care home. My parents are looking after me but they have not been getting much support. I should be getting 2:1 support in the day and 1:1 support at night. We had support for 5 days a week of 2:1 support for 7 hours a day, but it has suddenly been withdrawn. So now my parents are looking after me 24 hours a day, which is hard as I don't have a good sleep pattern and sometimes stay awake for most of the night. I usually go to sleep around midnight and often wake up in the middle of the night.

“ My care for my 36 year old son has completely stopped for the last 26 weeks, he needs 24/7 support which I am providing on my own, I am 67 and on just a state pension, no carers allowance as overlapping benefit. ...his daycare unit is making no effort to open but think they are working by sending colouring paper out and having zoom games which my son cannot join in or do.

“ Day centre shut, waiting for equipment from OT since last year.

Education stopping during COVID-19

A small number of people reported on the register their experiences of education, and reported education stopping during COVID-19.

“ Used to attend special needs school. Denied place since before lockdown even though I have EHCP, social worker and my parent is a keyworker.

“ School shut due to staff shortages prior to lockdown. We asked for [child] to continue attending. They said no but were doing a “risk assessment”. Not done. No communication. First week of May asked for [son] to attend from 1.6. Denied. CCG still not responded.

Cuts to support

As well as services and supports stopping completely, some people reported cuts to their support during COVID-19.

“ My daily care provision of 3x a day went down to 1x a day for 7 weeks. This meant I didn't get dressed for this period. I would be showered and put back into night clothes as no carer to undress me later in the day.

“ Support services changed from 9 hrs support to 3 x 5-minute phone calls.

“ The 'waiting list' group therapy sessions I was doing suddenly became a fortnightly check in call with no notice and no conversations with service users about whether this was what we wanted. I have had no contact with the rest of the people in the group since the beginning of March and am worried about how they are doing. Have only had contact from one of the group facilitators since March (the other was unwell) and these brief fortnightly calls are my only link into any service now. I asked about video calls, but it seems the Trust isn't even attempting to try them, even though I know other Trusts delivering the same treatment have moved to video. No reason given for why this is.

Services not providing reasonable adjustments/ flexibility

Many people reported that services were not adjusting themselves to their needs during the changed circumstances of COVID-19.

“ I have oral chemotherapy and collect tablets every month from the chemotherapy department at [local hospital]. My chemotherapy appointments were changed to another hospital, because of this my treatment didn't go to plan. When I arrived for treatment, my tablets were never there and I had to travel again to collect them, this happened for 3, the last being at my original hospital.

“ I receive 24 hour care at home, I have 3 personal assistants to look after my chronic health conditions. I need a lot of suctioning because I have a tracheostomy. My personal assistants had an appointment at the hospital to be fitted with the right masks, because 2 of them have a beard they would not fit them for that reason. I have been in touch with my CCG on a number of occasions and can't provide an alternative mask for all of our safety.

“ My GP practice is operating a telephone consultation system. I am deaf and cannot use the phone so have had to ask a close relative to phone for me which is completely unsatisfactory. There is also, as far as I can see, no way to make initial contact with the practice other than via voice calls by telephone. I have not seen a doctor but understand that they wear masks which would prevent lipreading. If I did not have a hearing person living with me and able to use the telephone I would have been in serious difficulty as the practice is closed to personal callers. I believe that this breaches the Equalities Act.

“ With a broken back and neck and limited (very) movement. How am I going to be able to pick up stuff left outside?

Care homes

A small number of people reported on the register their experience of living in a care home during the COVID-19 pandemic, with worries both about their safety and about their quality of life.

“ Someone in my care home has Covid 19 when I was told it was going to be safe as it locked down before anywhere else. I have dual sensory loss and been confined to my bedroom like a prisoner. My hearing aids have stopped working and staff said they could not get them repaired due to the virus so I couldn't hear my family on the phone when they rang, my only contact with the outside world.

“ In April Covid 19 swept through the care home. The manager had all the masks locked away except one per member of staff which had to be worn for 12-hr shift and the masks only had a 4-hr life also they were years out of date.

Services preventing people from going out or meeting family

A small number of people reported on the register that their service was preventing them from going outside or meeting family members.

“ *I haven't been out in 12 weeks. Staff refuse to take me out stating social distancing. I am self harming and my staff don't understand me. I am having lots of memories due to my trauma and abuse I suffered at [2 inpatient units].*

“ *I am used to going out lots and exercising - mainly walking. I enjoy this and it helps my health. I often do this with a family member and can't now as I am not allowed to see them as I don't live with them. My staff now take me out for occasional short walks - not as far as I normally walk and only a few times a week, when I was going out for a good walk with my family member nearly every day before. I am missing going outside and it's not helping my health. I am feeling fed up and my physical health is worse than before this all started.*

“ *Due to social isolation I cannot see my mother. Care support have started wearing masks and I am not allowed to go out. We are only 3 young men in my supported living household with a care team of 12 people. My mother is less exposed to the virus than any of the care team but I am not permitted to see her. Any time I look at a person their face is always masked, in my own home. I am not allowed to go out but everyone else of the population are allowed outside socially distancing. I can go outside for a walk without risking exposure but the care team won't let me.*

Shielding, self-isolation and the support being offered putting people at risk

Substantial numbers of people reported on the register difficulties and dilemmas associated with shielding or self-isolating (whether this was themselves, another member of the household, or support workers/personal assistants). Trying to minimise COVID-19 infection risk led to some people changing, reducing or not getting any of their usual support, with staffing patterns and an absence of PPE prominent issues.

“ *I am in a vulnerable group therefore shielding for 12 weeks and reducing the number of people coming into my home is important. In the first 2 weeks of shielding I had 3 different carers coming each week, this would not normally be the case it would be 2 at most. I phoned the company to explain my situation and was told if I wasn't happy I could cancel my care. I felt I had no choice and cancelled one of the days I had care. This reduced my care from 13 hours to 9 hours a week. I was struggling with 13 hours and only getting the bare minimum of care I need, now I am really struggling and my needs are not being met.*

“ *I am shielding. The care staff who come to me often don't have any PPE so I don't let them in.*

“ *Due to health conditions & medication, I am shielded during coronavirus outbreak. My PA has a partner who works delivering goods, two children in school and works for someone else as well as me, so as soon as shielding was advised I stopped PA coming into my home. Shopping is done for me, cooking by PA at their house & all brought to me. PA is taking prescription requests to my GP & collecting medicines for me. Luckily, I can cope with personal care & laundry, but looking after my home... not so much. Chaotic & not altogether clean; I'm sure PA will have it all organised come August, or whenever-it-is we are advised to stop shielding completely.*

“ My mum is 86 she has Alzheimers. She had two support staff attend her each morning to wash and change her clothing. This arrangement was in place for 16 months. The women supporting mum were very effective however, we asked them if they were provided with PPE, they were told by their manager “they did not require PPE“, even though the same support staff visited approximately 6-10 people each morning. This information was confirmed when I contacted the management of the agency. As a result I decided I could not put my mum or the support staff at risk. I cancelled the daily support in mum’s home and I took over the 24-hr support for mum. She remains well and happy. I am exhausted.

“ I have 10 staff who support me and during Covid19 I have had to get PPE for the staff which is either very expensive or difficult to obtain. I have had some PPE given to me from various places but just as a one-off. We are constantly looking for PPE online and not sure whether what we are buying is correct especially masks.

Paying for support

Some people reported having to pay for additional aspects of their care and support during the COVID-19 pandemic (often PPE, but also personal assistants), even when they could not afford it.

“ We have had to buy our own [PPE] at very inflated prices - no contact has been made about this.

“ I was charged £166.40 per week after a ‘light touch’ financial assessment to pay for social care. I only received benefits and couldn’t afford it. The council then removed the budget and won’t let me access it as I can’t afford to pay. I complained to local government ombudsman who closed down case due to coronavirus.

Help to get food/shopping or prescriptions

Many people reported difficulties getting basic supplies such as food and getting prescriptions.

“ I could not get a delivery slot as I am not on the 'extremely vulnerable' list. But my local covid support hub (run by local council) were quite difficult to access. I wasn't really 'in need' enough so they just emailed me a list of local shops that deliver. They said if I exhausted all other options, they might be able to allocate me a volunteer.

“ Carer and partner who has asthma has had to do everything. No contact from anyone. When she phoned council about help getting food etc she was told to ring back if we had no food for a couple of days.

“ I have been unable to have my normal cleaning and tidying service due to the issues surrounding Covid 19 so my house is a mess. I was unable to access online food shopping and ran out of many items forcing my housemate who is also disabled and at risk into the shops, he would sit in his car until the queue went down or sometimes drive around different shops to find one without a queue.

“ I have had to chase around multiple supermarkets websites, searching for a slot that someone can help me receive. Every week, it's almost become an obsession now. I am also having to do the same for my elderly parents as they are vulnerable too (my dad is 76 and diabetic) and not able to use a computer. I still can't get all the food and other items that we want/need. I even rang the doctor to ask for a shielding letter as I'd read that it was within their discretion to write me one, but was refused by a locum who doesn't believe that my condition, ME, exists - all I wanted from it was access to supermarket delivery slots, but was made to feel like a fraudulent scrounger.

“ My mum used to collect my medication from the pharmacist for me. I don't have it home delivered because it needs signing for and I have a lot of difficulty getting to the front door. I tried using a postal service, but because I take morphine they wouldn't accept me.

No assessment or future planning

Some people reported that planned assessments had been postponed or cancelled during COVID-19 pandemic, or that requested assessments due to changed needs or circumstances were impossible to organise.



Refuse to carry out a review due to Covid despite a dramatic worsening of condition.



I've requested a carer's assessment but I've been told I have to wait until staff are back in the office and/or are able to travel to visit me. Meanwhile the person I'm caring for is waiting for a reassessment of his personal budget, and isn't getting any increased funding to pay for PPE.



I am currently waiting for an ASD assessment. In January I was told the wait was 12-18 months. I have received no update since the Covid outbreak, but I am assuming I will have an even longer wait now, as it is unlikely that any assessments have been able to take place during lockdown.

Back-up planning

Some people reported the back-up plans they were considering in the event of COVID-19 infection, or their worry about the absence of a back-up plan.



There is no back up plan! That's the problem! The pandemic has highlighted this. Our lack of help is because we have been left to cope on our own. The government gave us the money so we get our own help but the flaw in the system is that there is no back up. As a result of my failing energy, I may need more help as my body struggles more and more. I may end up in the situation where I won't be able to get out of bed. Then I will need much more help!



Nothing as of yet, I have relocated to my girlfriend's house, as its easier for me here with my assistance dog and as she is a key worker in the NHS, she is helping me keep safe.

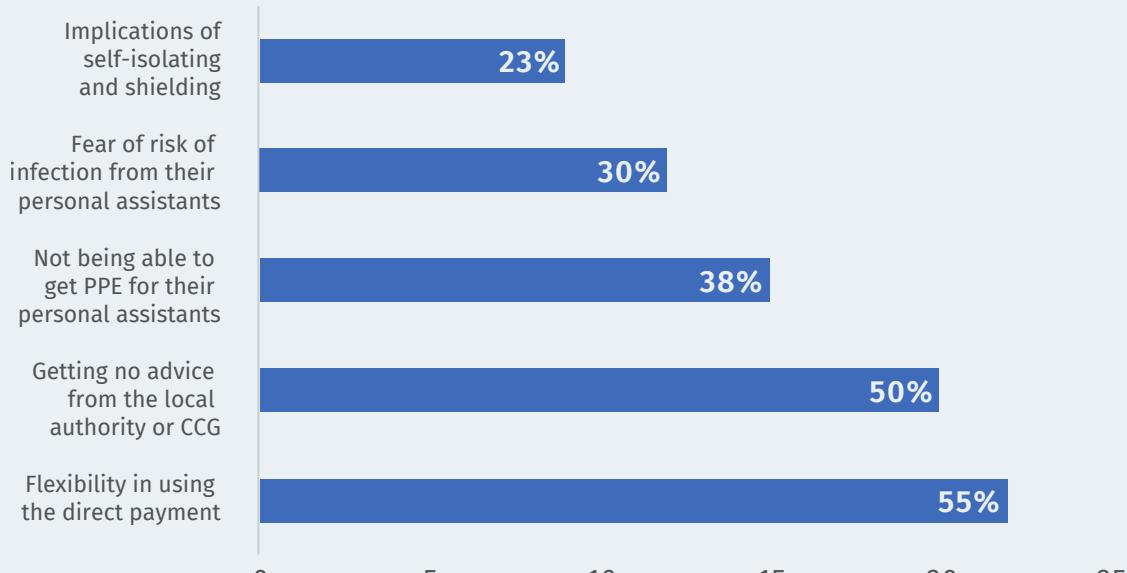
“ I have been left without any organised support from local authorities. Although I used the council website to register for support, a whole month on I have yet to receive a reply. When I called was told to go to the website that told me to register, having already done this I felt my options ran out. My backup plan is what I put together myself. It's a plan of hope rather than substance or certainty. I hope someone will bring food, I hope if I need to see a doctor I will be able to. Keep my fingers crossed I don't burn myself or have a fall in the shower. So the plan is, should something happen I am eventually found before being fully decomposed. The council has looked after only those they previously provided services to for social care and forgot everyone else.

“ Nothing has happened to me as the carer yet, but as people get out and bolder, this is only a matter of time. I am extra worried being of the BAME community.

Direct payments

The 40 people registering an experience about their direct payment were asked about what aspect of their direct payment they wanted to register (they could pick as many as they wished), what happened, and what reason they were given for what had happened.

Issues people registered with regard to their direct payment



With regard to direct payments, people most commonly registered issues about flexibility in using the direct payment (22 people; 55% of those registering an issue with their direct payment), followed by getting no advice from the Local Authority or CCG about if the person's care network breaks down completely (20 people; 50%), people not being able to get PPE for their personal assistants (15 people; 38%), a fear of risk of infection from their personal assistants (12 people; 30%), and the implications of self-isolating and shielding (9 people, 23%).

Across all these specific issues, people most commonly reported that the reason the issue had happened was due to poor communication (30 reports) or that people did not know why the issue had happened (23 reports). All other reasons given were rarely reported (6 or fewer reports).

Many people wrote in about their specific situation, and all these statements were organised into four broad themes: flexibility, accessing PPE, personal assistants, and contact from the council/CCG.

Flexibility

Some people reported their council being flexible in how they could use their direct payment during the COVID-19 pandemic.



My PAs have been amazing throughout. My Local Authority has been responsive and flexible



I have been given flexibility with my DP and have been able to use contingency monies for extra support. The extra funding was given within 24 hours when I had a deterioration in health.



Supposed to use funding for activities in community. However local authority have been good enough to be flexible so my carer can come to the house and do activities with me rather than Mummy not getting any break at all.

Others reported poor communication from councils or CCGs and a lack of flexibility, with consequences in terms of support.



Council will not allow me to pay a family member. I have lost 2 members of staff during the Covid and I am not able to recruit new staff, my family are taking unpaid leave to care for me. My local authority will not allow me to pay my family member for the care she is providing.

“

I had a PA who needed furlough really as I was told to reduce care to minimum PAs. One had no work but I was told I'd need to clear it with budget holders to lower wage or furlough. Legally my insurance said I could pay a retainer fee but too stressful to keep going through managers who are not the employer yet want to take control of hours and wages despite guidance. In the end they are being left on full pay.

“

I had an agreed care package with PAs that was then removed without any consultation and was told I would have to have an imposed agency package instead. I have severe physical and MH disability and the agency had absolutely NO experience of MH and could not guarantee to provide ANY continuity of care. It was unsafe. The local authority has not once responded to a single enquiry by email or telephone as to why this was done and that I challenge the changes imposed.

“

My personal assistants left and I have been unable replace them. I gave my direct payment back to the council and asked them to organise my care through the commissioned route. This is not happening.

Accessing personal protective equipment (PPE)

While a small number of people reported good support and extra funding to access PPE, a more common experience was a lack of clarity about how to access PPE, no extra funding for PPE, and poor or delayed PPE provision.

“

I was supplied with PPE when I was unable to access it, but also given information on how to access. I was given extra funding to support this.

“

No one could even provide a list of suppliers for PPE.

“

I asked social worker if I could purchase PPE for support worker via direct payment-for my daughter. I still don't have answer, what to do??

“

Been told to pay for my own PPE for my care team.

“

More or less sorted although they failed to fulfil the order of masks, gloves and aprons - even though it was agreed. I was given masks only at one point - the other items were there but left in the cupboard.

Personal assistants (PA)

With regard to PAs, people reported PA support reducing or stopping altogether, usually due to people trying to manage COVID-19 infection risks.

“

Had to reduce PA team from 4 to 2; 1 PA is living with mother who is on 12 week shielding list. 1 has another job, his other employer is also on shielding list. The remaining 2 PA's are fantastic/reliable etc, but I fear what will happen if either of them are unable to work due to Covid-19 symptoms or any other reason.

“

Between lack of PPE, not being in control of hours and pay etc my poor staff are stressed. Otherwise they have been so understanding of things not in my control.

Contact from the council or Clinical Commissioning Group (CCG)

Reports of positive experiences in terms contact from councils or CCGs were rare; more commonly people reported councils or CCGs refusing to engage altogether or having limited and unclear communications from them.

“

I want to say I have had great contact with my social worker. She is brilliant. I have regular contact with her. I get the right care and support I need. I am in the process of getting a few things sorted out with my care and support and it is being dealt with very well. I receive my care and support through direct payments.

“

Very little contact from social care only wanting to know if I was using my direct payments.

“

Took a good few weeks (4-6) to gain any information/guidance re way forward. We need clarification on whether we can furlough PA's, nothing is clear.

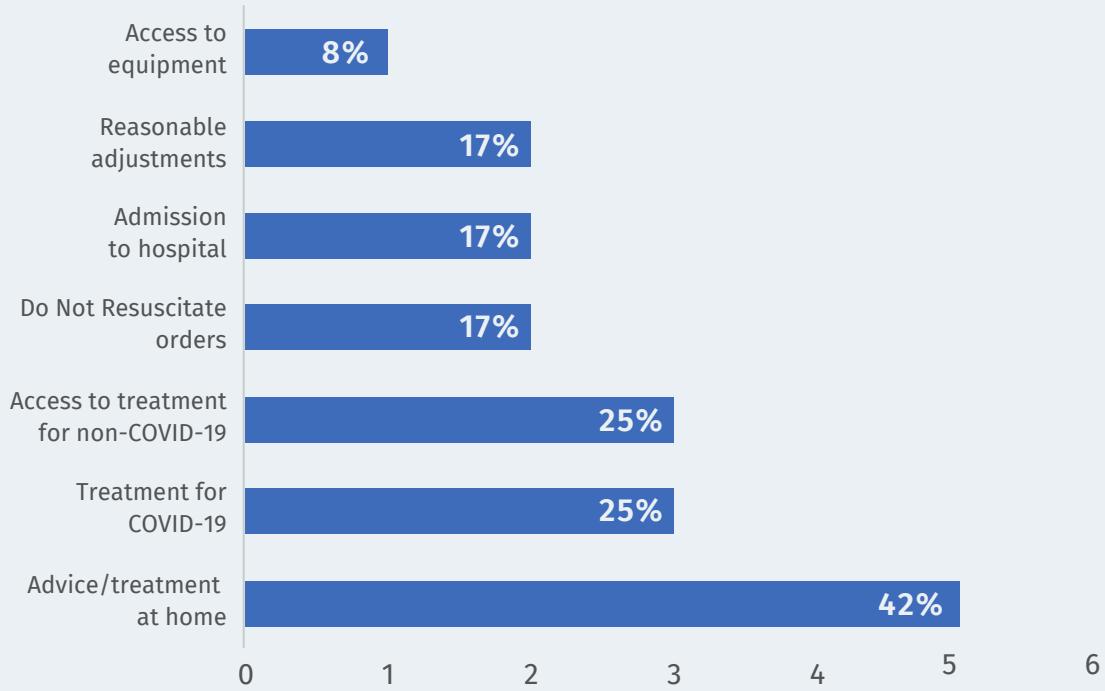
“ My direct payments have been stopped despite still having a carer for my son. I was also called to say I will be getting a new social worker for my son. This person hasn't called, I have called numerous times and never contacted back. My son is severely disabled and the help and support from social care is shocking.

Testing and treatment for COVID-19

The 12 people registering an experience about testing and treatment for COVID-19 were asked about what aspect of their experience they wanted to register (they could pick as many as they wished), what happened, and what reason they were given for what had happened.

With regard to testing and treatment for COVID-19, small numbers of people mentioned: advice/treatment at home (5 people); treatment for COVID-19 (3 people); access to treatment for a non-COVID-19 health condition (3 people); Do Not Resuscitate orders (2 people); admission to hospital (2 people); reasonable adjustments/accessibility of services (2 people); access to equipment (1 person).

Issues people registered with regard to getting testing and treatment for COVID-19



Across all these specific issues, there was one report that the reason the issue had happened was due to poor communication and 4 reports that people did not know why the issue had happened.

In written comments, people spoke about the attempted imposition of Do Not Resuscitate orders (DNARs), problems with getting COVID-19 tests and the unresponsiveness of health services to potential COVID-19 symptoms.

“ *Letter telling me to shield told me to pack a hospital bag and take DNR - I found this pre-emptive and upsetting.*

“ *I was given a phone call from my GP asking if I would sign a DNAR form (Foregoing a bed and ventilator was the exact quote). They were not clear in what they were offering, and made it sound like “in the event that there was someone more in need would I give it up to save a life.” It was moralising and not clear that I would have essentially had signed away my right for treatment. Luckily I did not accept, but I’ve heard from other charities that they have had to legally challenge unlawfully DNAR.*

“ *I wasn’t tested straight away and there was no question of DNAR until they realized I was from a care home. The staff made the ambulance crew give me oxygen.*

“ *I have been advised that I am no longer able to live alone at home so I have to move to a care home. My family found me a care home willing to take me as an emergency admission subject to a negative Covid 19 test. My son arranged online for a drive-through test and we went for the test. We still have not had the results despite my sons making several calls to the Covid help desk Public Health England and 111. My son had to get the local MP involved and she got to the top of PHE and they have admitted my test cannot be found, they assume it’s lost and one of the ones sent to America for testing. I have had to have another home test today. Thankfully my social worker and sons have managed to keep my place open in the home ready for me to finally move. The telephone service totally useless no-one knew how to find my results or how to go about contacting anyone who may have known how to get them.*

“ *I have had possible Covid, the NHS 111 Covid service does not record phone calls, does not contact doctors and simply say stay at home for 7 days. Advisors speak from a script so do not listen to what you are saying.*



Photo: Gabriella Clare Marino on Unsplash



I can't
do it

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