



Supporting people
with sight loss



Access Social Care

Helplines Data Collaboration Group

The State of the Nation

June 2022

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Executive summary

Every day, millions of older and disabled people are denied the social care they need. Most local authorities cannot meet the growing demand for care, and none are confident they can meet their legal duties in the future. This affects all of us because we will all need social care at some point. We all have a right to hold public bodies to account, but millions of us cannot afford lawyers so rely on legal aid. The 77% reduction in community care legal aid cases since 2010 means we have nowhere to turn. Without access to justice, our rights do not exist. The rule of law is broken.

It is widely acknowledged across the political spectrum that the resources available for social care have not risen at the same rate as demand. And yet, data gathered on this critical issue by local authorities and central government about unmet need for social care remains inadequate, if we are to fully understand the level of both rising demand and existing service provision. The Association of Directors of Adult Social Services reported in May 2022¹ that 6 in 10 councils were having to prioritise assessments and are only able to respond to people where abuse or neglect is highlighted, for hospital discharges or after temporary residential care support for recovery and reablement. The report also highlighted that over half a million people are waiting for assessments, reviews or care and support to begin.

Access Social Care leads this data collaboration project in partnership with helplines at Royal Mencap Society, Age UK, Carers UK, Independent Age and RNIB. We also welcomed Ealing Advice Consortium this year whose data will be included in our analysis from July 2022. We combine reflections from our work supporting people with care and support needs with findings from this project to describe the emerging themes in social care advice provision.

Our second State of the Nation report explores the increasing need that people have for social care advice, highlights the external factors which may have driven some of this increased need, and details the complexities of some of the issues that those in need are now facing.

This report draws together over 74,000 separate data points through a bespoke processing pipeline built and maintained in collaboration with Owen Bowden, Insight & Analytics Lead at Royal Mencap Society. We have matched over 1,200 separate organisational data categories to a set of harmonised group categories ('universal themes'). These universal themes match similar group member queries into one category (further information on process at Annex B), allowing us to derive greater collective insight across the sector. We categorise member data into group types: '**carers**', '**older people**', '**sensory disability**' and '**learning disability**'. We explore key social care trends, investigate the changing pattern of advice provision and detail some examples of the impact this has had on people with social care needs and their families. Due to the specific availability of 'sensory disability' data, 'sensory disability' is included in the 'Quarter 4 2021/22 and Quarter 4 2020/2021' only.

We observe an unprecedented level of advice provision over and above what we reported in our 2021 State of the Nation report. People continue to struggle in accessing care and support and the increases in advice provision in many of our universal theme areas are stark.

Please contact the author of this report with any questions Hannah.hewish@accesscharity.org.uk

¹ [Adass](#)

Key findings

Our members have provided advice on more social care advice queries in the year 2021/22 compared to 2019/20, a rise of **74%**.

Our members processed **88%** more enquiries that were identified as needing specialist legal advice in the year 2021/22 compared to 2019/20.

The number of enquiries about social care needs assessments has risen by **229%** in the year 2021/22 compared to 2019/20.

The number of people contacting our members about problems or concerns about existing social care and support rose by **43%** in the year 2021/22 compared to 2019/20.

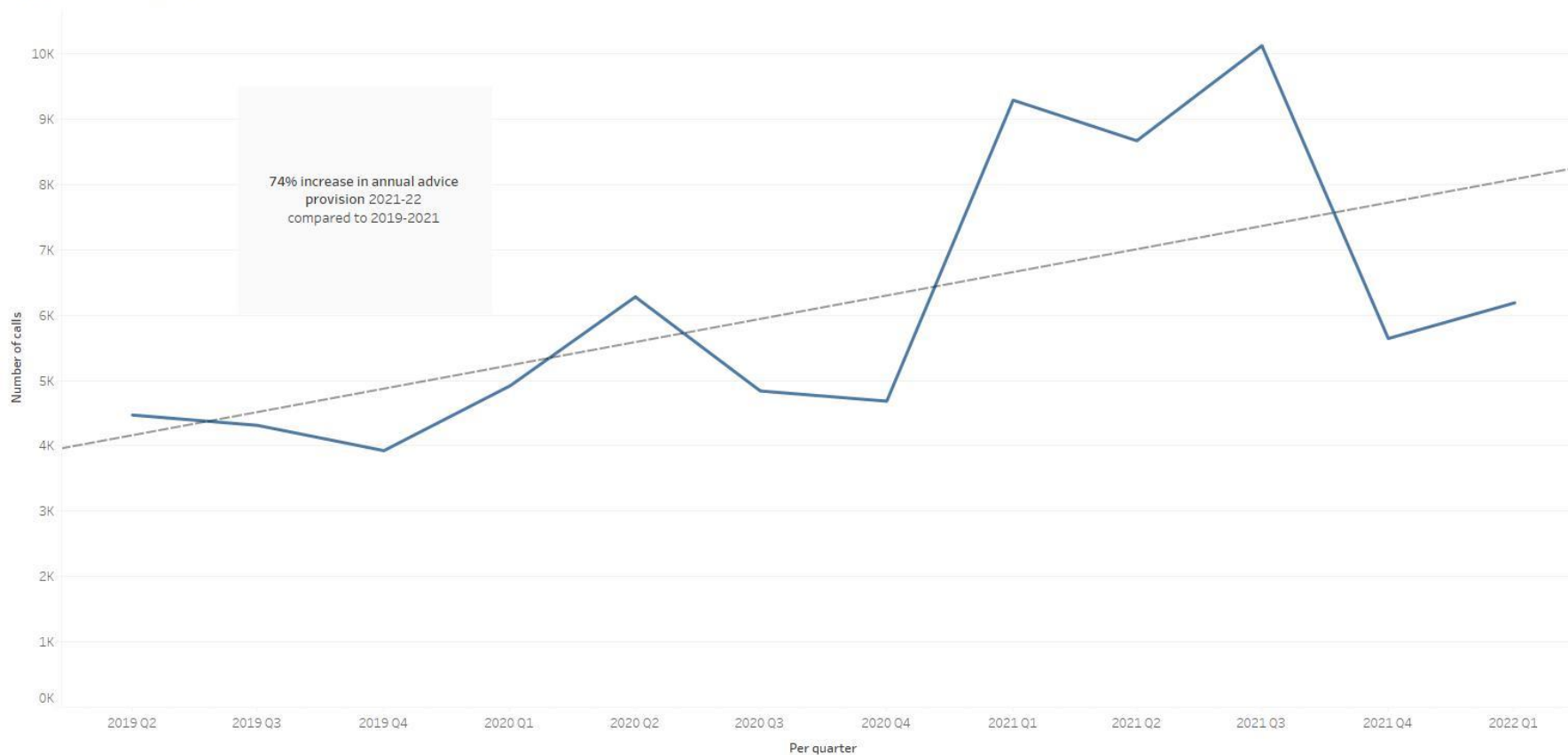


Advice provision

Advice provision

Learning disability, carers and older people

April 2019 to March 2022



This year, our members have processed 74% more queries in 2021/22 than during the pre-pandemic 2019/20. We know many of our members took operational decisions to expand their advice team capacity to meet growing demand in 2020/21. For example, Carers UK doubled their call centre opening times which helped to process a significant increase in queries in the first and second wave of COVID-19. Many of our other members expanded their advice offer in the same year of 2020/21 by extending opening hours or employing more staff to process additional demand. What is currently hidden from view, is the overall demand for social care advice as our members are not in a position to report on those calls that they do not have capacity to answer.

Although the data suggests an apparent dip in demand for advice in the later part of the year, this does not reflect the reality of the situation. Several of our members have experienced COVID-19 health and staff related pressures which meant at times having to restrict opening hours over the winter period of 2021 and as a result, advice provision on our universal themes capture reduced for some members from October / November of 2021 (noting that overall contact volume is likely to have remained higher than this).

Despite these variances, the increase in people requesting support from helpline organisations is stark. The issues being reported to helplines are of growing concern against the backdrop of more financial savings by local authorities most of whom continue to need significant cuts to be made to their adult social care budgets.

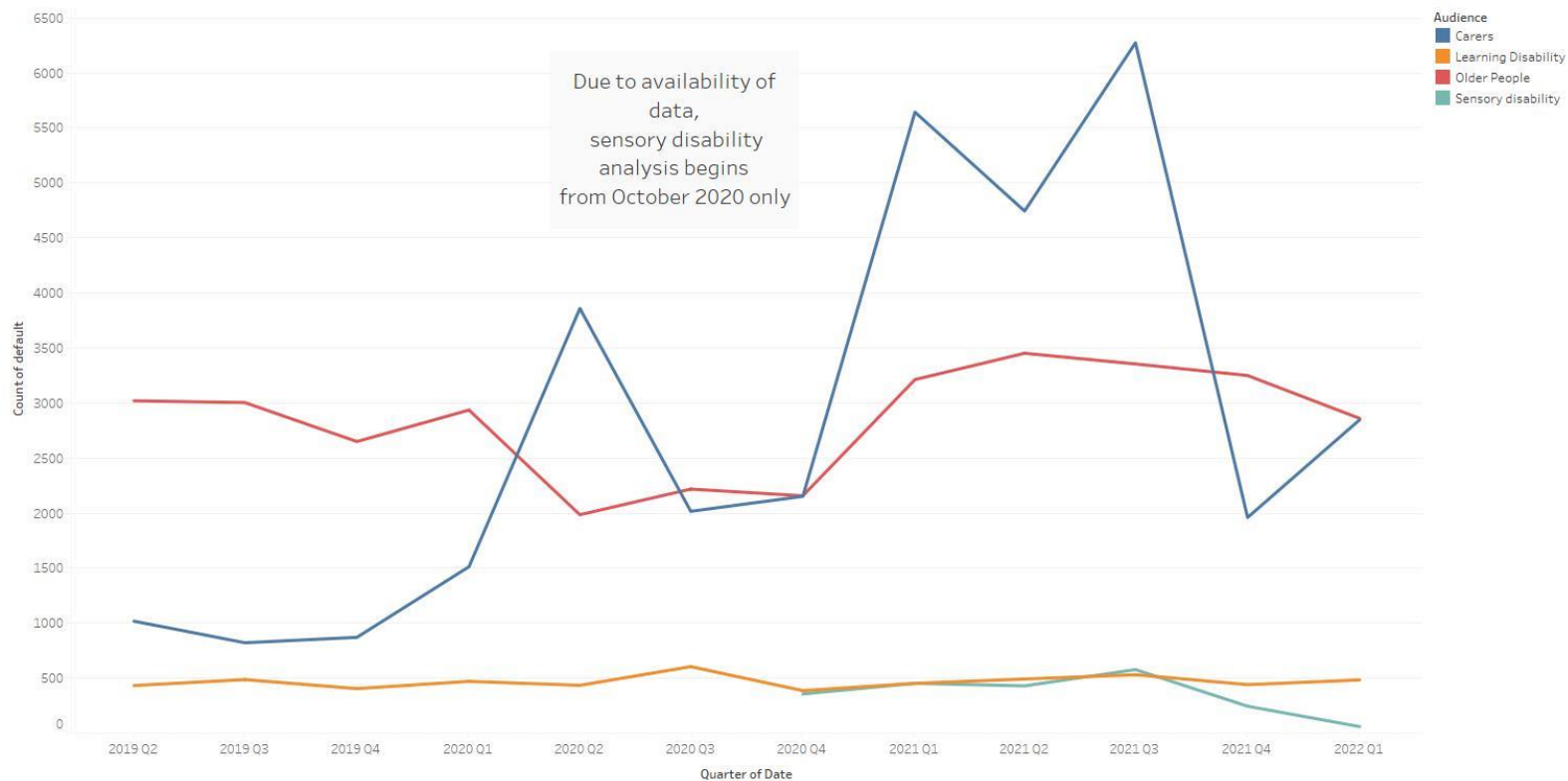
Common themes for this cohort within our universal themes include:

- Queries about assessments, both for the person with care and support needs and their family carer
- Not enough hours of support or losing support entirely
- Cuts to services
- Delays in assessments and delivery of care and support

Audiences: Carers, older people, learning disability, sensory disability

All audiences

April 2019 to March 2022



Only the helpline contacts that match our project’s universal themes are logged against our data categorisation and so the above charts do not reflect overall helpline call volume, which is higher. *As noted above, sensory disability is included from October 2020 only.*

Audience: Carers

In this context we are referring to informal carers such as family members or friends, rather than paid support. ‘The Kings Fund Social Care 360’ report estimates that these informal carers contribute an equivalent of 4 million paid care workers to the social care system each year.

We have seen an increase in enquiries from carers during this period. This increase, coupled with the types of issues people are calling about, highlight real concerns around the lack of information informal carers are receiving about their rights as well as a lack of support for themselves and those that they care for. Common queries within our universal themes include:

- Queries about assessments, both for the person with care and support needs and their family carer. These assessments are often vital steps towards securing additional support for carers, such as respite support
- Not enough hours of support or losing support entirely (for examples when day centres closed)
- Cuts to services, including respite services
- Delays in assessments and delivery of care and support

In addition, carers are facing many other issues which indirectly impacts on their ability to get appropriate support. For example, there has been a marked increase in the last six months of carers reporting problems registering with their GP as a carer. An increasing number of carers are being told by their GP that they are not carers or do not qualify for carer support, or for things like priority access to the COVID-19 vaccine. The impact of this is huge and many carers are left at breaking point.

Carers UK states:

“Unpaid carers are at breaking point, exhausted after more than two years of caring with little or no outside support. The impact on a social care system that was already on the brink of collapse before the pandemic means even more pressure on even more families who are propping up a chronic shortage of services.

“With hundreds of thousands of people now waiting for an assessment or service, sustainable funding for social care is essential, without which many thousands of carers and families will simply be unable to cope much longer. Together with the impact of the cost-of-living crisis, we’ll see the unacceptable inequalities that unpaid carers and their families already face, widen.”

Audience: Learning disability

People with a learning disability and their friends, family and informal carers continue to feel the devastating costs of the pandemic on the type, level and amount of support they receive.

For those in this cohort, the most frequent queries within our universal themes include:

- Concerns about the support they are currently receiving from the local authority either in the number of hours they receive or the type they receive
- Information about adult social care assessments
- Support in finding an advocate to help them navigate the social care system

Royal Mencap Society states²:

“Social care is not “fixed” as the Prime Minister once promised, and that is painfully obvious in the new figures from the Association of Directors of Adult Social Services (ADASS)¹. We know many people with a learning disability, their families and those working in social care are paying the price of a system ravaged by the pandemic - services are still closed, staff are spread too thin, and ultimately people's lifelines to the outside world are being cut off.

New research by Mencap has also revealed widespread loneliness amongst people with a learning disability and almost a third (32%) are struggling with their mental health, with many people still stuck at home in the aftermath of the pandemic because of reduced social care support. Mencap is urging decision-makers to act now to provide community support to prevent further isolation and irreparable damage to the mental health and wellbeing of people with a learning disability. We also need to see longer-term funding targeted at supporting decent pay rises for social care workers, many of whom are paid far too little and will be hit hardest by the ever-increasing cost of living.”¹

Audience: older people

For this cohort, the most frequent queries within our universal themes include:

- Queries about how much they are required to pay for their care, including whether the local authority has calculated this correctly
- Queries about eligibility criteria for social care, including what to do when they are told they do not meet certain criteria

² [“Social Care is Not Fixed”: Mencap Responds to New ADASS Figures | Mencap](#)

- What to do when they are not getting enough support or are getting poor quality support

In response to the May 2022 ADASS survey (as above)³, Age UK states:

"These new figures make for grim reading and behind them are real older and disabled people whose lives are being sadly diminished by lack of essential support. They highlight how desperate things are at the moment in social care, because of shortages of money and staff, so I hope Ministers will stop trying to claim that they have 'fixed social care'. It would be fantastic if they had but unfortunately there is clearly an awful lot more for them to do. Meanwhile, hundreds of thousands of older and disabled people are having to put up with a ramshackle service, with more than half a million unable to get even to first base by having an initial assessment."

"I'd love to be able to give people some hope by suggesting that once the Government's care reforms start to come in next year, things will start to improve. The problem though is that this wouldn't be true, because their changes really only relate to how much financial support people get in paying for their care, they won't do anything to expand the help available or improve its quality and reliability, and that's what many older people and their families tell us worries them the most. After all, what's the point of having the reassurance that you won't face unlimited bills for your care, if there's no one to provide it for you in the first place?"

"The Government deserves great credit for committing to improve social care, after all its recent predecessors chose to look the other way. However, Ministers are at grave risk of being seen to over-promise and under-deliver on their promises, as this latest ADASS survey demonstrates only too well. It's an utterly miserable situation for many older and disabled people, as it is for all the committed people who work in social care, alongside those who commission services in local authorities, who know they have no chance of meeting local needs."

³ [Adass](#)

Audience: sensory disability

Sensory disability is included in our analysis for our quarterly comparisons **only**. The most frequent queries within our universal themes include assessment queries, such as delays in getting assessments, queries about eligibility and information-seeking on issues such as how to access specialist support where they are finding this difficult. In response to the living with COVID-19 plans, RNIB stated:⁴

“With Covid legal restrictions being lifted, it’s essential that the needs of disabled people are genuinely taken into account and reflected in Government policy. Blind and partially sighted people faced unique challenges during the pandemic with their needs often overlooked; many people didn’t always receive vital letters on shielding in accessible formats while the reality of social distancing was often impossible. We also had to fight to ensure people with sight loss were considered a priority group when it came to booking online food deliveries.

“We urge the Government to truly consider how they can best support blind and partially sighted people as we move to a new normal, such as continuing the work to ensure Covid tests are accessible. Whatever the future pattern of Covid infections, it’s vital that the impact of Government policies on blind and partially sighted people is factored in from the start, and not as an afterthought.

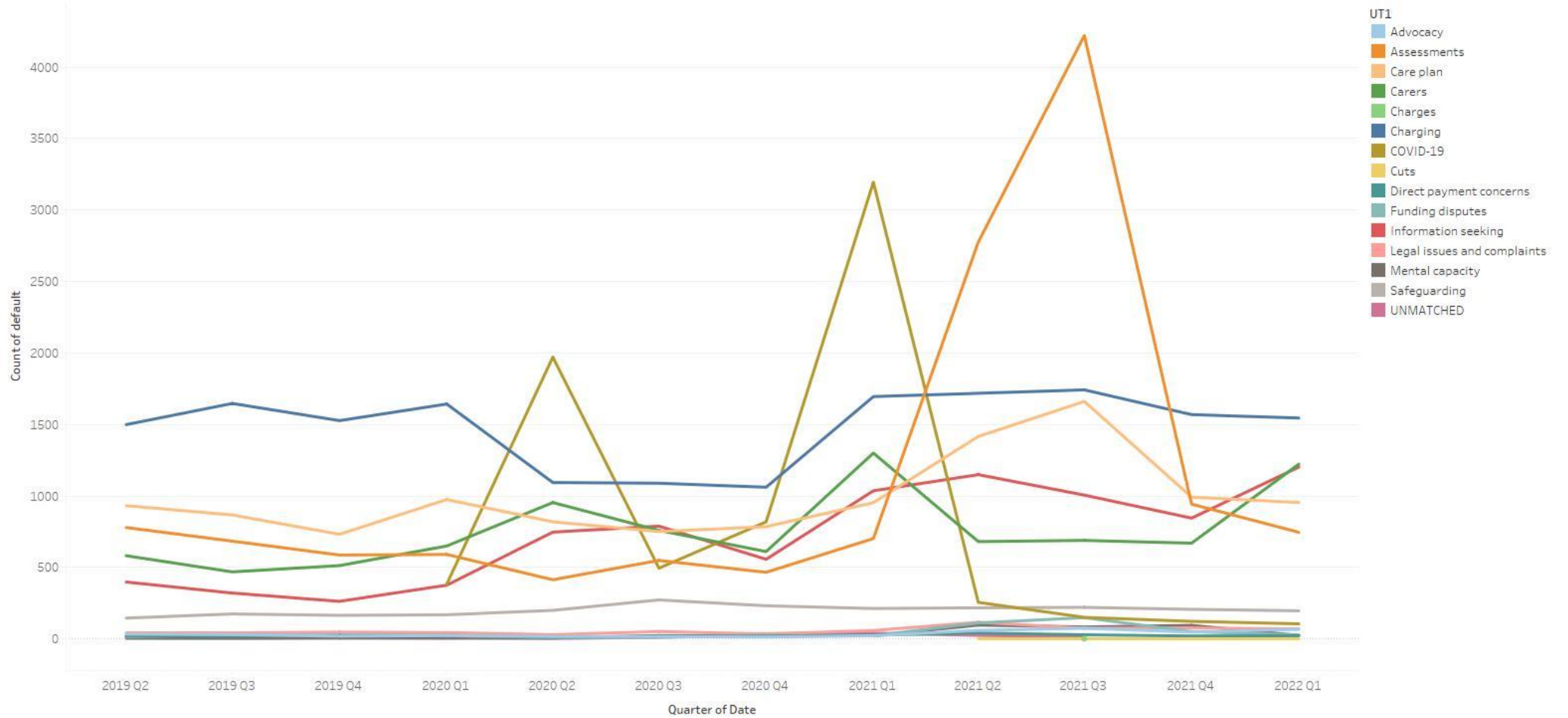
⁴ [Response to the Prime Minister in the House of Commons announcing the new living with Covid plans - RNIB - See differently](#)

Thematic analysis: 2019/20 and 2021/22

Universal themes

Learning disability, carers and older people

April 2019 - March 2022



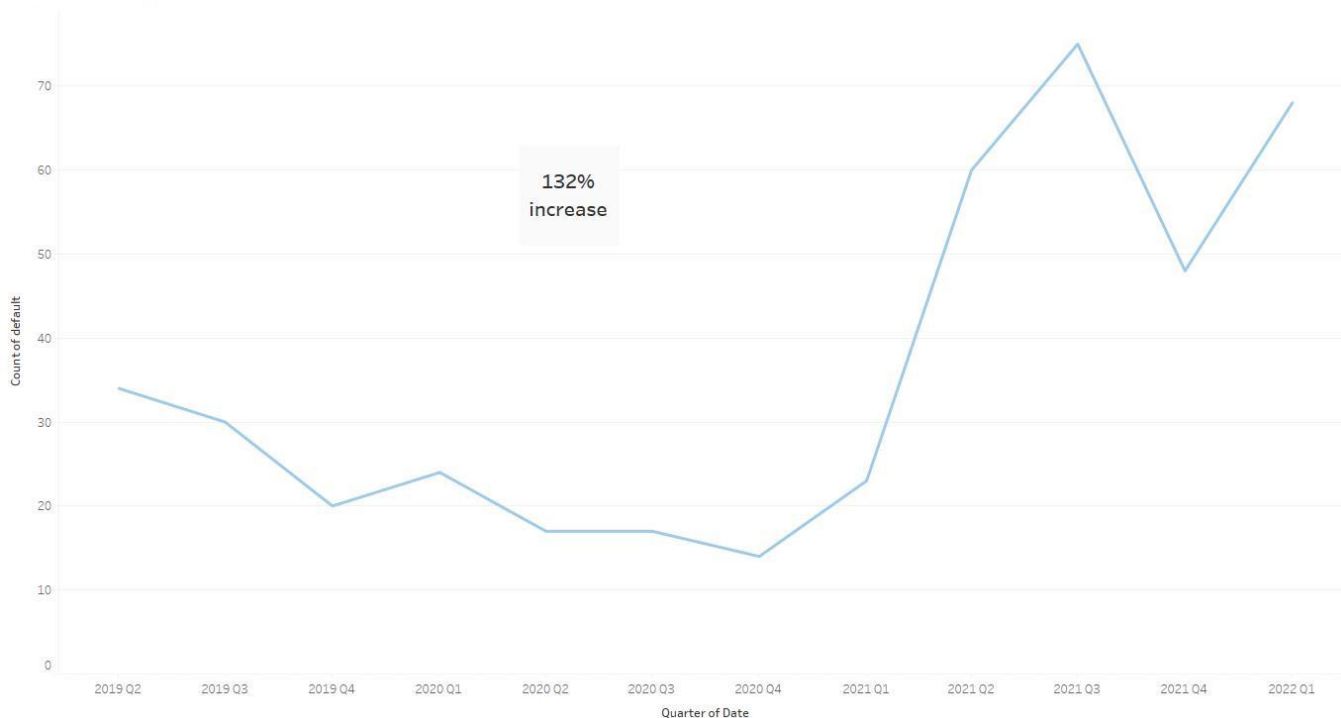
Assessments overtook COVID-19 as the theme seeing the biggest increase this year, rising to unprecedented levels.

Advocacy

Advocacy

Learning disability, carers, older people

April 2019 - March 2022



Our group members saw a sharp increase in requests for advice about statutory advice services. These services are required where a person (or their family carer) would otherwise have 'substantial difficulty' taking part in the care and support process. The test is entirely distinct from whether a person has mental capacity. It is therefore an integral part to ensuring that an individual's voice is heard by statutory services when making pivotal decisions about whether someone should get care and support, and what that should be. Some of these will be simple questions asking how to access statutory advocacy services but will also include queries about what to do when someone has been refused an advocate. Some enquirers report that they are simply told that they (or more often their family member/friend) have capacity to take part in the care process so do not require an advocate. However, in reality, they will struggle to meaningfully take part and would have substantial difficulty in doing so alone.

B had autism and learning disability and was supported by Access Social Care. They lived in supported living accommodation with three other people. They had limited understanding of the care and support process and in the past, they had always been supported by their Mum during assessments or reviews. Their Mum had become increasingly physically unwell and consequently could no longer support B at a forthcoming assessment. B's care provider warned the social worker that B's Mum could no longer support B and that an advocate was needed.

The social worker attended anyway and carried out an assessment of B with only his care manager present. The assessment stated that B could cope with a reduction in support hours and lost 10 hours of 1:1 support. We supported B to secure a new assessment to be carried out with support from a statutory advocate.

There is no government data collection on the use of Care Act 2014 advocacy services, and the latest Independent Mental Capacity Advocacy data has not been updated since 2014⁵. It is not possible to truly understand the level and nature of people's needs in many cases without this data, and it is an important measure which could be combined into future data capture in line with the government's 2022 Data Saves Lives Strategy⁶.

⁵ [GSS adult social care statistics interactive database \(civilservice.gov.uk\)](https://civilservice.gov.uk/gss-adult-social-care-statistics-interactive-database)

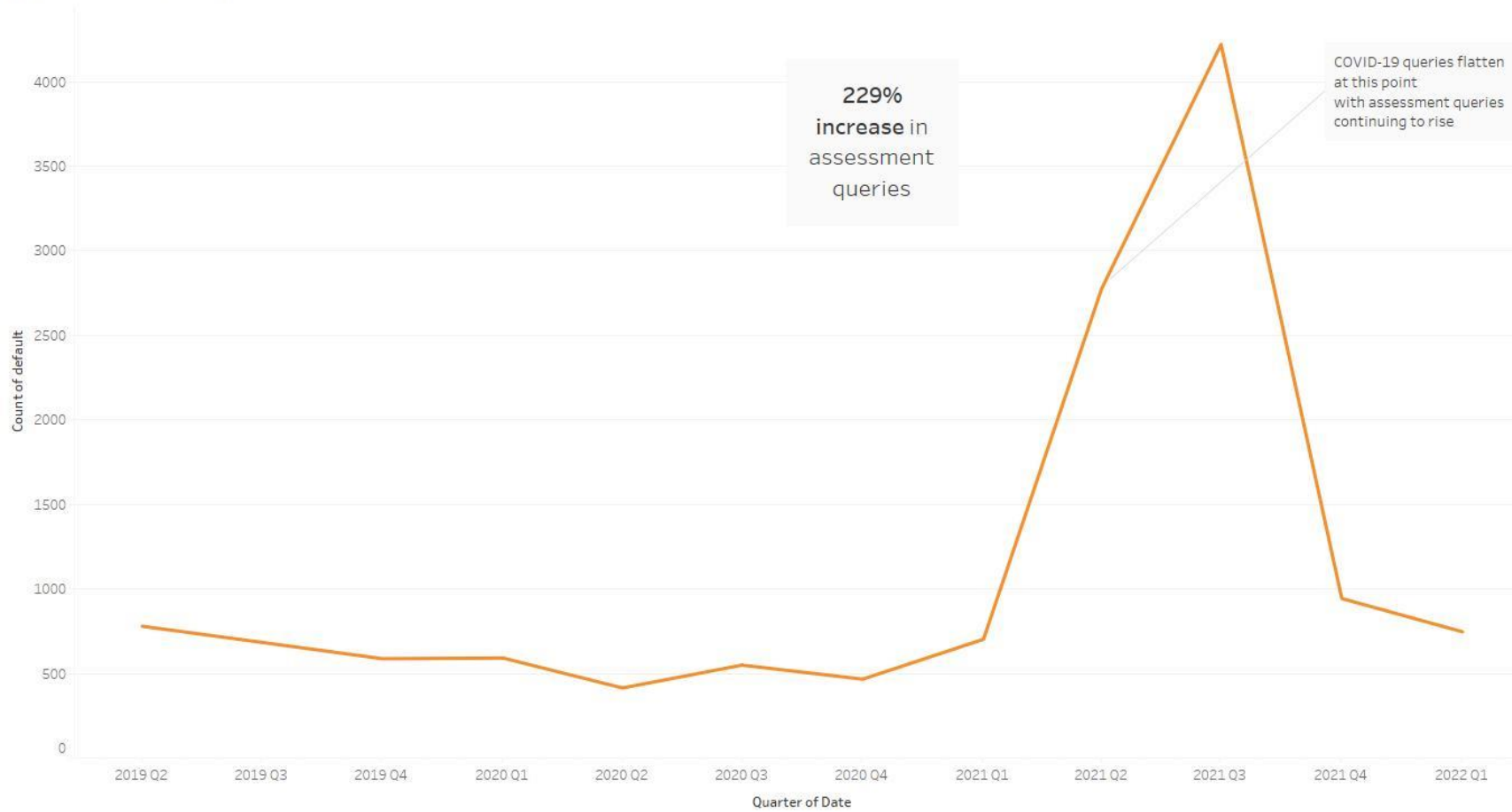
⁶ [Data saves lives: reshaping health and social care with data \(draft\) - GOV.UK \(www.gov.uk\)](https://www.gov.uk/data-saves-lives-reshaping-health-and-social-care-with-data-draft)

Assessment

Assessments

Learning disability, carers, older people

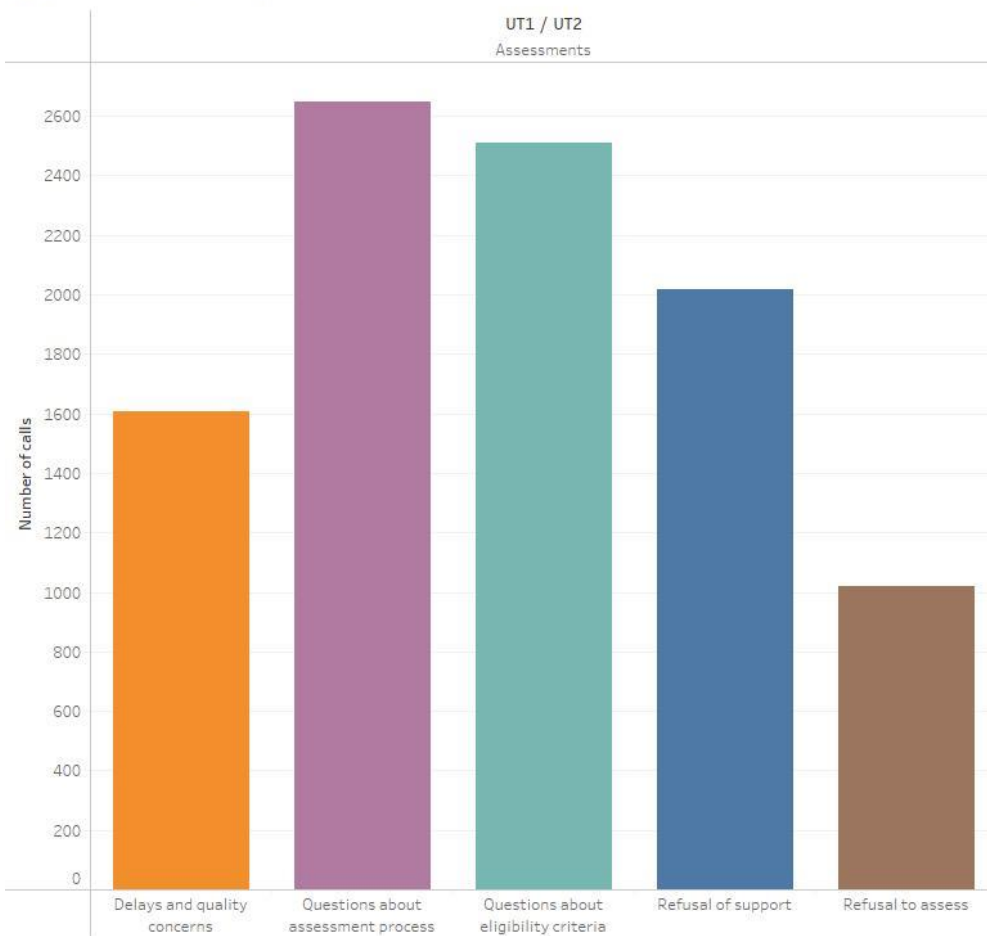
April 2019 - March 2022



Assessment

Carers, learning disability and older people

April 2019 - March 2022



Assessment

The assessment and eligibility process is one of the most important elements of the care and support system. The process must be person-centred throughout, involving the individual and those supporting them to have choice and control.

The assessment process starts from when local authorities begin to collect information about the person, and will be an integral part of the person's journey through the care and support system as their needs change. It is a gateway to care and support that individuals need in order to live fulfilled lives, and can also be a critical intervention in its own right⁷, which can help people to understand their situation and the needs they have, to reduce or delay the onset of greater needs, and to access support when they require it.

The queries about assessments vary in type, including:

- Questions about how to get an assessment, and what it will entail
- What to do when a local authority refuses to assess someone
- Concerns around delay in getting assessments or the quality of the assessment
- People being told verbally that they would not meet the criteria for local services but who have not yet had a statutory assessment under s9 Care Act 2014
- Delays in getting an assessment despite the local authority agreeing to carry one out (with some people being told they are on long waiting lists)

We are concerned that the increasing number of enquiries about assessments, coupled with the delays people are already facing, points to a system on the verge of collapse. This dire situation is only going to worsen due to growing demand, as 500,000 people are awaiting assessments or care and support provision alone⁸.

In the Access Social Care response to local authority guidance on fairer charging 'Supporting local implementation'⁹, we highlighted the fact that adult social care funding

⁷ [Care and support statutory guidance - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/61222/care-and-support-statutory-guidance-chapter-6.pdf) Chapter 6

⁸ [Adass](https://www.adass.org.uk/)

⁹ [Access Social Care responds to consultation on 'Supporting local preparation – draft guidance' \(accesscharity.org.uk\)](https://www.accesscharity.org.uk/wp-content/uploads/2021/03/Access-Social-Care-responds-to-consultation-on-Supporting-local-preparation-draft-guidance.pdf)

reforms will increase demand for assessments, reviews, and care planning processes. This is because approximately 125,000 self-funders¹⁰ will want to enter the system to ensure the cost of their care is attributed to the lifetime cap. In addition, by increasing the upper capital limit, more people will now qualify for local authority funded care. The number of people self-funding care and support in supported accommodation or receiving domiciliary care are currently unreported, although plans to collect client level data are underway¹¹.

The delays that individuals are facing in obtaining assessments is a recurring theme seen in our cases at Access Social Care. In some cases, the local authority says it simply does not have enough staff to carry out assessments. In one recent case, we spoke with a person who had already been waiting for 4 months for an assessment and had been told they were waiting to be allocated a social worker. They were told it would be a long wait, because there were 600 cases and only seven social workers.

We are extremely concerned about the lack of additional funding to support the social care sector with this huge increase in demand, and detail further steps that can be taken in our consultation response to Supporting Local Implementation.¹²

¹⁰ [Care homes and estimating the self-funding population, England - Office for National Statistics \(ons.gov.uk\)](https://ons.gov.uk)

¹¹ [Data saves lives: reshaping health and social care with data \(draft\) - GOV.UK \(www.gov.uk\)](https://www.gov.uk)

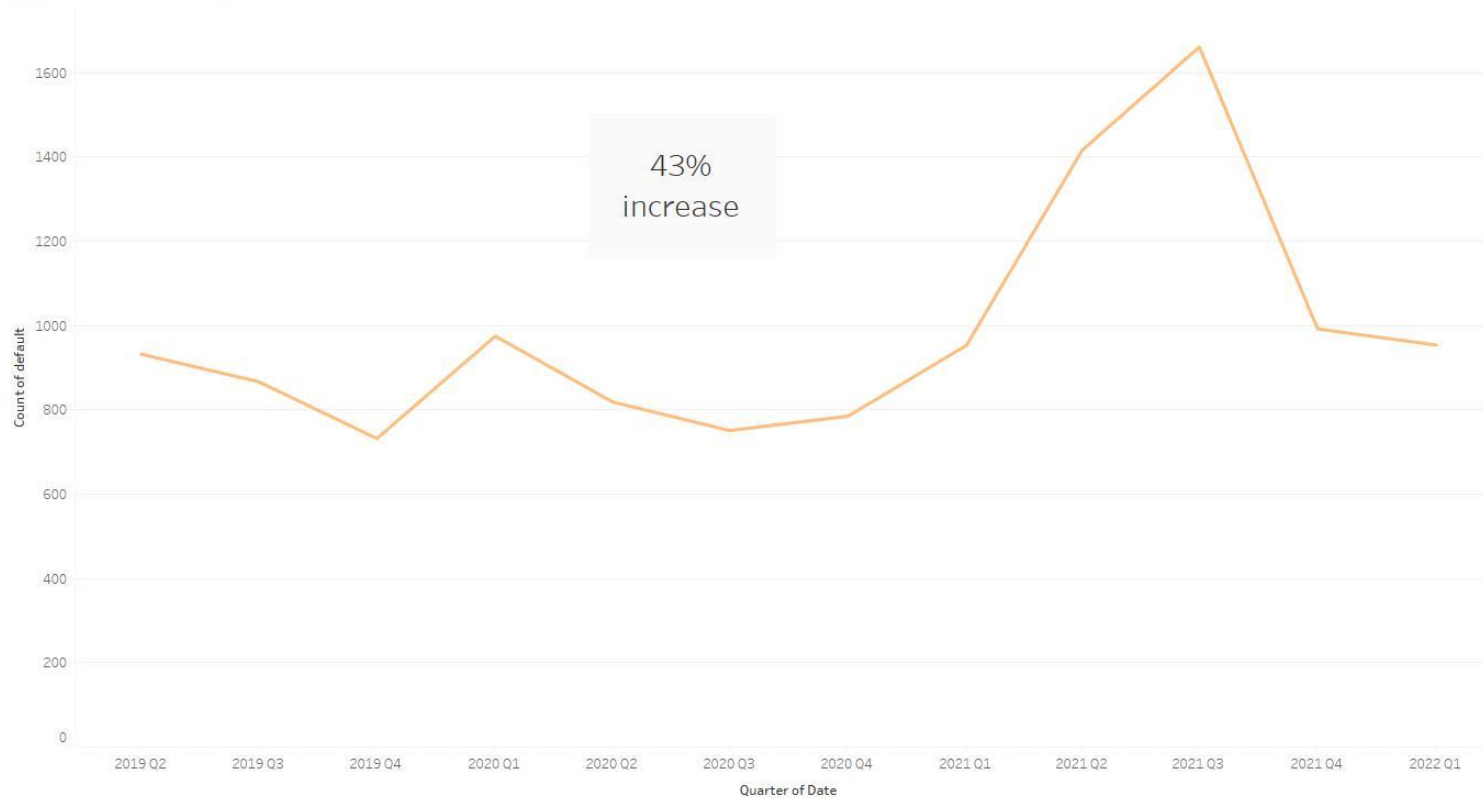
¹² [Access Social Care responds to consultation on 'Supporting local preparation – draft guidance' \(accesscharity.org.uk\)](https://accesscharity.org.uk)

Care plans

Care plans

Carers, learning disability and older people

April 2019 - March 2022



Following the needs assessment and determination of eligibility, a plan must be provided where a local authority is required to meet needs¹³. 'Meeting needs' is an important concept under the Care Act 2014 and moves away from the previous terminology of 'providing services'. This enables a greater variety of approaches in how needs can be met, developed through care and support planning as described in the Care and Support Statutory Guidance¹⁴.

So, for those who have managed to get over the hurdle of obtaining an assessment and secured a care plan, data shows that the challenges for individuals do not end there. Enquiries about care plans include:

- Ongoing problems with existing care and support
- Problems with the amount allocated to pay for their care and support
- Being told they cannot choose the type of care and support they receive
- Asking questions about how to review their care plan
- Lack of appropriate 1:1 hours where a person clearly has significant need warranting significant 1:1 hours
- Lack of available staff due to the workforce crisis
- Inappropriate offers of residential care which do not meet a person's needs, for example a 25-year-old with autism being placed in a care home for elderly people with dementia



The Association of Directors of Adult Social Services reported in May 2022 that almost 170,000 hours a week of home care could not be delivered because of a shortage of care workers during the first three months of 2022 (4). That is a dramatic seven-fold increase since Spring 2021¹⁵. This shortage is being seen in the enquiries our members are receiving, with some individuals being told there are not enough staff to meet their care needs.

For those asking for advice on care plan reviews, it is often because they think their needs have changed or are different, or that new support is required. Many of our members advise people who raise concern that a care plan is out of date and no longer truly represents the needs of their loved one. This in turn leads either to individuals not having their needs met or care providers having to provide the additional care at their own cost.

¹³ [Care and support statutory guidance - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/106482/care-and-support-statutory-guidance.pdf) paragraph 10.9

¹⁴ [Care and support statutory guidance - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/106482/care-and-support-statutory-guidance.pdf) paragraph 10.10

¹⁵ [Adass](https://www.adass.org.uk/)

The shortage of social workers, with a national vacancy rate of 9.5%¹⁶, further means that reviews of care plans are often delayed or in some cases do not take place for years.

Access Social Care supported C in 2021. C had learning disability and autism and lived with her parents. Due to the significant pressures during lockdown, including major changes to her routine (lack of day centre support and loss of respite care), C's needs had increased, and she required significant 1:1 support both in the home and out in the community. It was widely acknowledged between C's parents, the social worker, and the local authority that she needed a care plan review but that there was a long waiting list. They waited 8 months by the time that they received advice from us, and were in a dire position emotionally and financially, with one parent having to stop work to care permanently for C. Huge delays and backlogs in the system caused significant distress for C and her family.

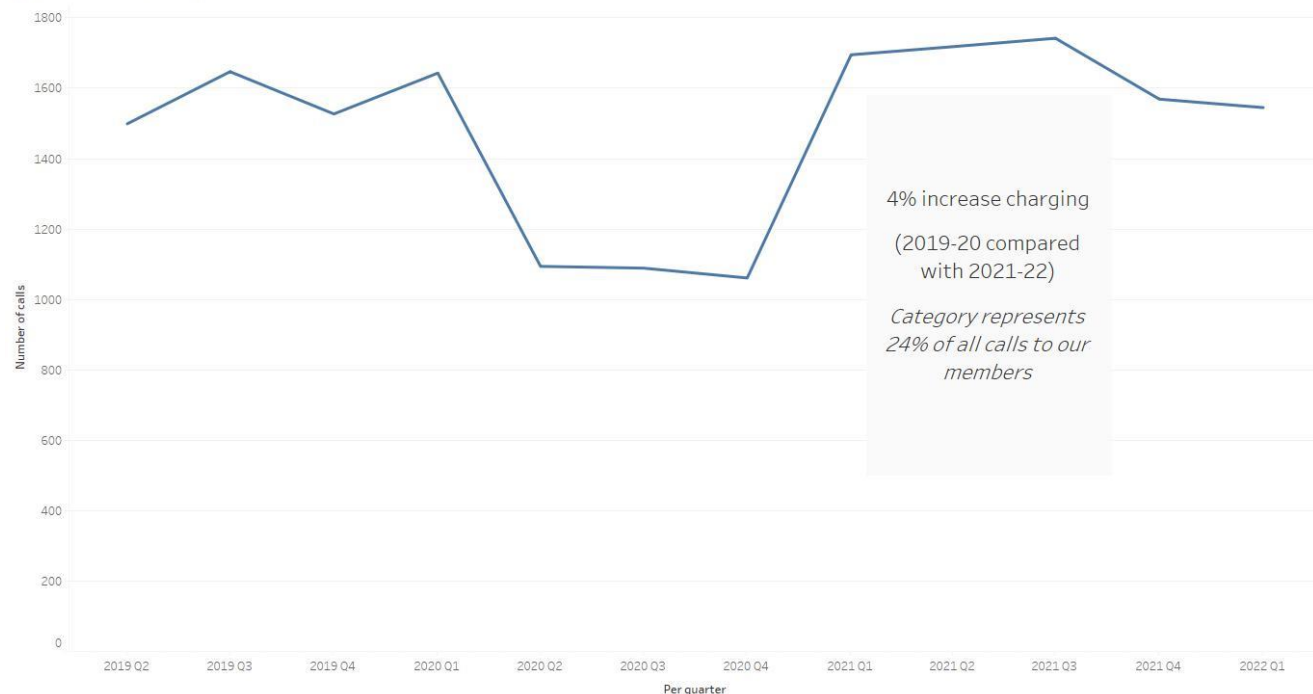
¹⁶ [Drop in adult social workers employed by councils as vacancies and turnover mount - Community Care](#)

Charging

Charging

Learning disability, carers and older people

April 2019 - March 2022



Charging refers to the amount of money a person is asked to pay for their social care. The Care Act provides a single legal framework for charging for care and support. It enables a local authority to decide whether or not to charge a person when it is arranging to meet a person’s care and support needs, or a carer’s support needs.¹⁷ We describe below in some detail the current themes and future changes expected in 2023 which are likely to affect people in receipt of care and support.

Because a person who receives care and support outside a care home will need to pay their daily living costs such as rent, food and utilities, the charging rules must ensure they have enough money to meet these costs. After charging, a person must be left with the minimum income guarantee (MIG), as set out in the Care and Support (Charging and Assessment of Resources) Regulation 2014. In addition, where a person receives benefits to meet their disability needs that do not meet the eligibility criteria for local

¹⁷ [Care and support statutory guidance - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/consultations/care-and-support-statutory-guidance) paragraph 8.1

authority care and support, the charging arrangements should ensure that they keep enough money to cover the cost of meeting these disability-related costs.¹⁸

Enquiries about charging include:

- How local authorities should calculate the amount someone should contribute
- Disability related expenditure, the amount a local authority should disregard in calculating care charges
- Not being able to pay for care charges: having to choose between care or a full food shop
- Being invoiced a large, backdated sum for care and support without understanding how the local authority had arrived at that figure

Whilst the cost of living is a concern to all of us, it is likely to hit those in receipt of social care particularly hard for the reasons set out below.

Although the MIG has been increased, the increase was calculated in October 2021 when the rate of inflation was 3.8%. With inflation now standing at 7.8%¹⁹, and expected to reach at least 10% this year, it is extremely likely that individuals paying towards their care will not have enough money left over to buy the essentials. In addition, the rate of inflation is likely to be higher for items such as fuel and heating, items which those in receipt of social care often rely on more heavily.

Alongside this, our research indicates that many local authorities are seeking to use charging as a way of balancing their adult social care budget. This may explain the enquiries our members are receiving about Disability Related Expenditure, which is the amount of money a local authority should take into account to reflect additional costs that people face relating to their disability. These costs are then considered when a local authority calculates the amount of money a person should pay for their social care. The process is designed to make sure that a disabled person really does have enough money left to live on after paying for their care and support. However, many enquirers report that their true Disability Related Expenditure is not considered by their local authority, leading to social care charges which can be wholly unaffordable.

People in this situation face a bleak prospect of choosing to pay for care or pay for their food, as reported by several of our member organisations. One person in contact with Access Social Care is only able to attend one day activity a week rather than the two stated in their care plan, as they can't afford two taxi fares. Transport is not included in the plan or allowed as a 'Disability Related Expense'. We know of several people who had to hand back their support packages as they cannot afford to pay for them.

With fairer cost of care reforms and the lifetime cap on care costs of £86,000 due to be implemented from October 2023 (and January 2023 for 5 'trailblazer' areas: Wolverhampton, Blackpool, Cheshire East, Newham and North Yorkshire), it is possible that our members could see an increase in enquiry volumes as these changes are



¹⁸ [Care and support statutory guidance - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/108242/care-and-support-statutory-guidance.pdf) paragraph 8.42

¹⁹ As at 19th May 2022 [Inflation and price indices - Office for National Statistics \(ons.gov.uk\)](https://www.ons.gov.uk/economic-indicators/inflation-and-price-indices)

implemented. This is because approximately 125,000 more people will be coming into the system seeking assessments. We do not know exactly how many people this affects, but we do know that within care homes alone there are an estimated 125,000²⁰ self-funders. To benefit from the cap, these people will require an assessment of their needs, something which they will have never needed before, putting further pressure on the system.

We anticipate a possible increase for our members in charging queries over the next 12 months relating to the cost-of-living crisis and the changes described above. We will monitor changes to the nature and volume of enquiries received by our members about social care charges in our quarterly interim updates to this report.

²⁰ [Care homes and estimating the self-funding population, England - Office for National Statistics \(ons.gov.uk\)](https://ons.gov.uk)

Legal issues and complaints

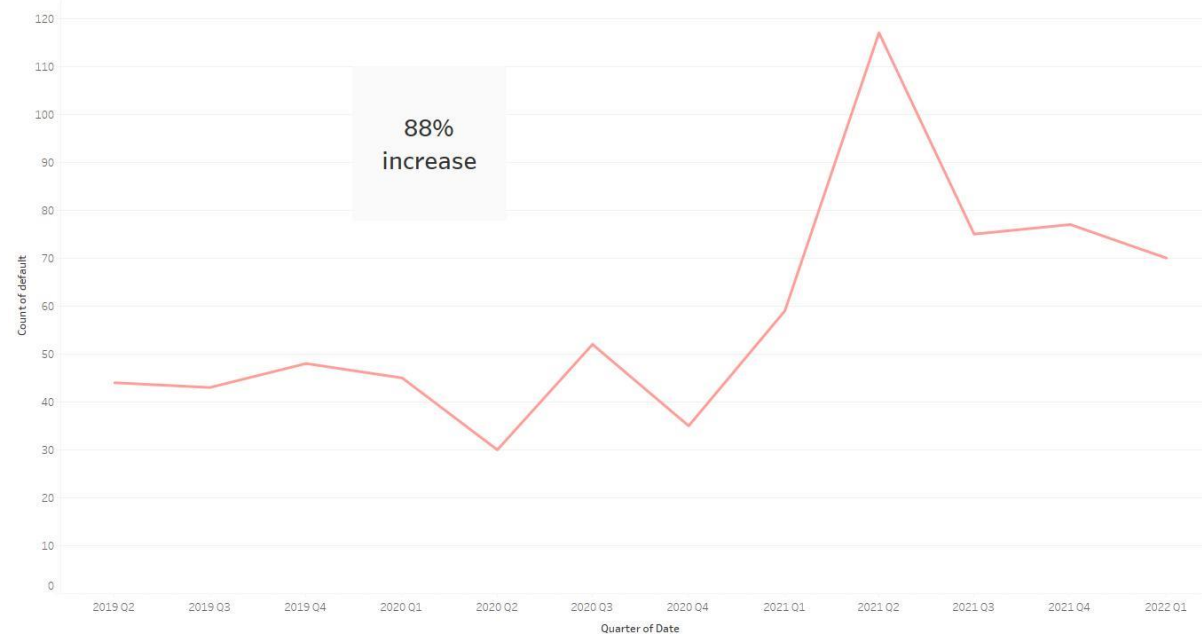
The number of people contacting our members for advice on how to access specialist legal support increased by 88% in 2021/22 compared with 2019/20.

People may need specialist legal support to understand and enforce their legal rights. They may need advice on whether their case should, for example, be heard in the Court of Protection, or whether there are any other public law remedies that may be a helpful route of redress. More people are reporting that they are experiencing problems with social care issues, for example the significant increase in assessment problems detailed above.

Against the backdrop in this increase in need, there has been a staggering 77% decrease in people accessing community care legal aid since 2010. Our research²¹ shows that accessing legal aid for community care law has become increasingly difficult because it is loss-making for law firms, meaning many people in need of this specialist legal advice are unable to access it.

We note below, in our quarterly analysis, an even greater increase between 2020-2021 (120%). Some people affected by problems detailed within our set of universal themes require specialist legal advice on these complex issues. Many of our members signpost or refer to specialist law firms. However, we know from our Career Pathway Report that there has been a 77% reduction in the number of new community care cases opened in the last 10 years, with lawyers telling us that it is loss making to take many of these cases on. Therefore, the service is not necessarily there to meet demand. We also know from Law Society research that 67% of the population, or over 40 million people, do not have access to a Community Care legal aid provider in their local authority area.²²

Legal issues and complaints
Learning disability, carers and older people
April 2019 - March 2022

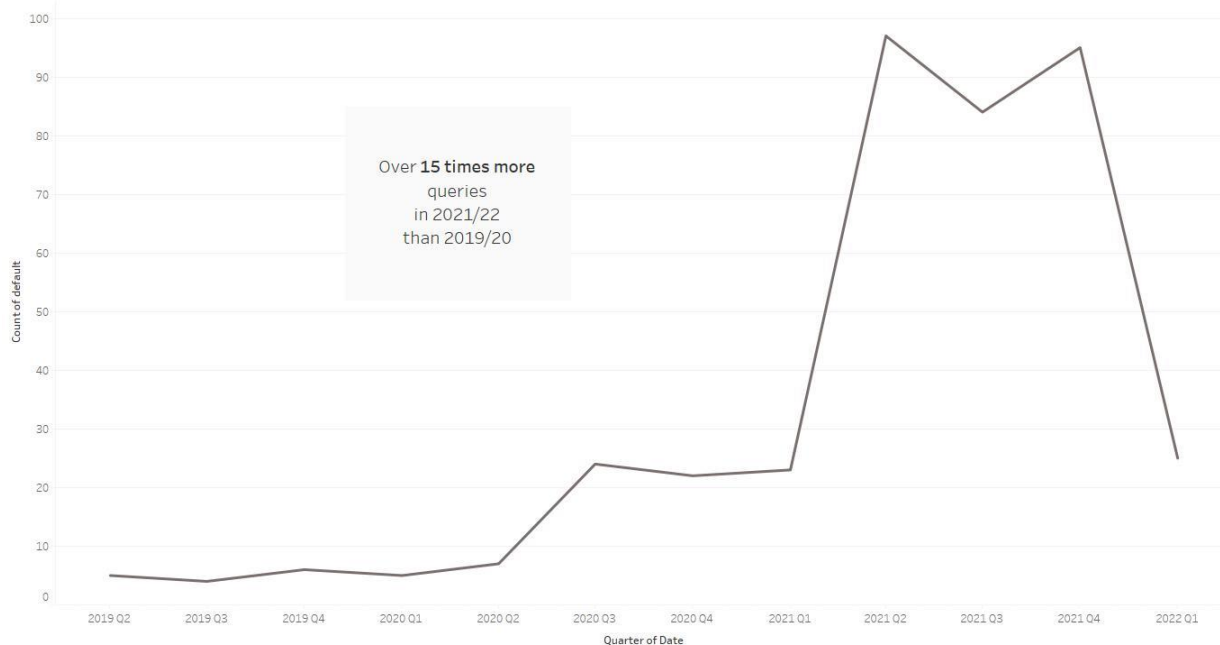


²¹ ['Loss-making' rates behind decline in community care work | News | Law Gazette](#)

²² [Community care – legal aid deserts | The Law Society](#)

Mental capacity

Mental capacity
All group members
April 2019 - March 2022



Mental capacity is a measure of someone's ability to make a decision for themselves. Mental capacity assessments look at whether a person can go through the process of making an informed decision.

Mental capacity enquiries have rapidly increased, seeing 15 times as many enquiries in 2021/22 compared to 2019/20. These queries dip at the start of 2022, in part at least relating to seasonal variances in helpline call volumes (with the period of October/November to January/February usually receiving fewer queries).

The types of queries around mental capacity include:

- Disputes over the need for a capacity assessment
- Disputes over the quality of the capacity assessment
- Understanding what is known as the 'best interests' process

- Concerns that an Independent Mental Capacity Advocate had not been appointed (which is different to statutory advocacy referred to above)

While these queries make up a smaller element of our overall data set, disputes over mental capacity can, in some circumstances, lead to the most significant breaches of an individual's liberty or can put an individual's safety at risk. These decisions can include whether a parent with a learning disability should be allowed to parent their child, locking an individual in their room at night, and making decisions about where an individual should move to in order to receive care.

Some of our members supporting older people note that extended care home or hospital stays across the pandemic, and lack of familiar and routine human interaction, has caused cognitive ability to drop, meaning that more people lose capacity to make certain decisions.

We provided advice to J's family in 2022.

J lived in residential care. The local authority carried out a new assessment and identified that J should move into supported living accommodation. J had significant complex cognitive and physical needs and had lived at his residential home for over 10 years. He was happy there.

J's family raised concern about the proposed move and were told that J was happy with the proposal and had agreed that he would like to move to new accommodation. J's family requested that a mental capacity assessment was carried out to establish whether he had capacity to decide where to live. The local authority stated that J had capacity and that they did not need to carry out an assessment as he was happy with the move.

We supported J's family to secure an appropriate Mental Capacity Assessment supported by an Independent Mental Capacity Advocate.

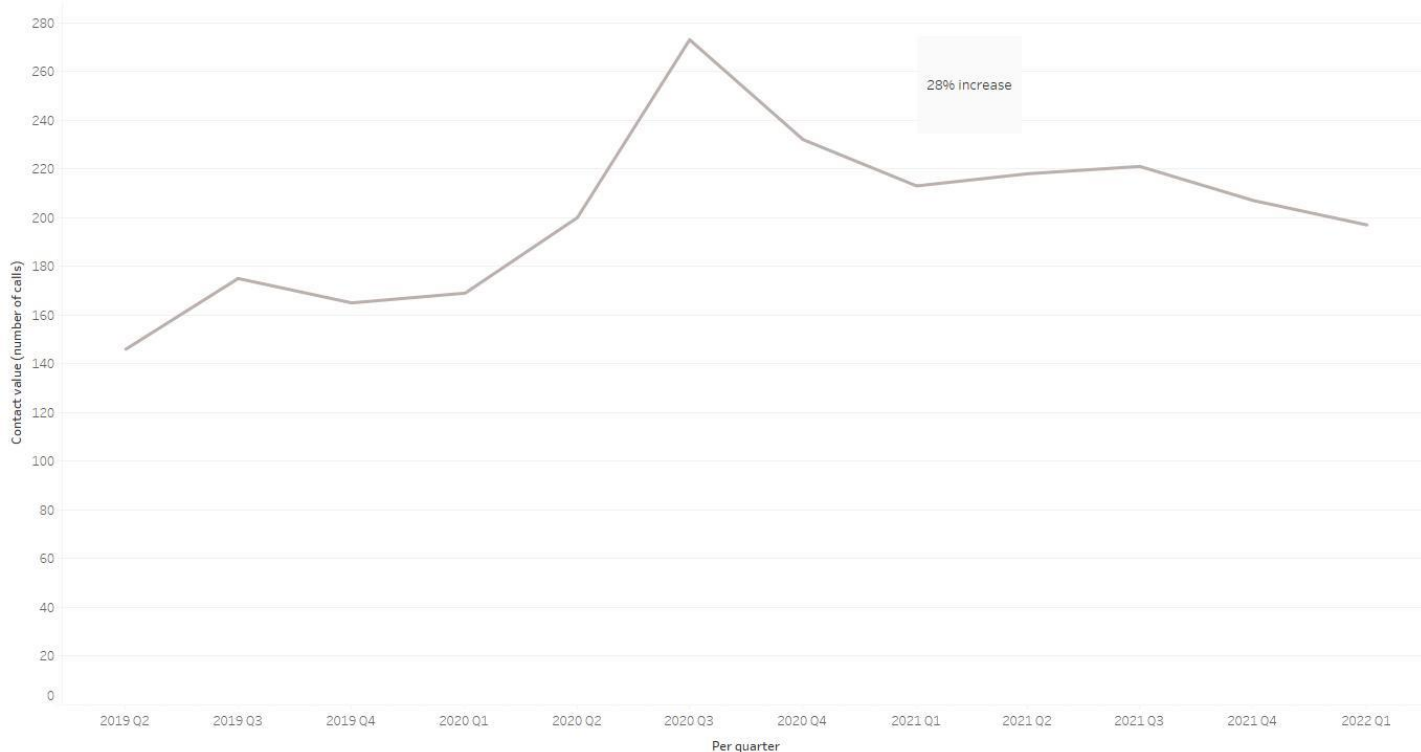
Safeguarding

Safeguarding is a term used to describe how we protect adults and children from abuse or neglect. It is an important shared priority of many public services, and a key responsibility of local authorities. Safeguarding is about protecting certain people who may be in vulnerable circumstances. These people may be at risk of abuse or neglect due to the actions (or lack of action) of another person. In these cases, it is vital that public services work together to identify people at risk, and put steps in place to help prevent abuse or neglect²³.

Safeguarding

All group members

April 2019 - March 2022



We reported in our State of the Nation report 2021 that some of the safeguarding referrals related to family carers feeling isolated, lonely and increasingly depressed in the second wave of the pandemic, suicidal amid their caring responsibilities. Very sadly, growing concerns about family carers have continued into 2021/22, with a significant increase in the safeguarding issues shown above relating to carers who are now in effect self-neglecting due to total burnout having cared for their family member with very

²³ [SD8: Office of the Public Guardian safeguarding policy \(web version\) - GOV.UK \(www.gov.uk\)](#) Paragraph 4.1 and 4.2

little support for the past two years. Some carers report they are forgetting to take medication or forgetting to eat sufficiently. In many circumstances, it is likely that this could have been avoided had they received the appropriate support they had requested.

Some family members raise safeguarding concerns to their local authority and receive an unsatisfactory response. One of our members advised a mother of a young woman who was self-neglecting and getting into dangerous situations. The situation was raised with the local adult safeguarding board, but no action was taken on the basis that they stated she had capacity to make unwise decisions. They had not carried out a proper capacity assessment and closed her case.

Quarterly comparisons – 2020 and 2021 further analysis



October – December 2020 and October to December 2021

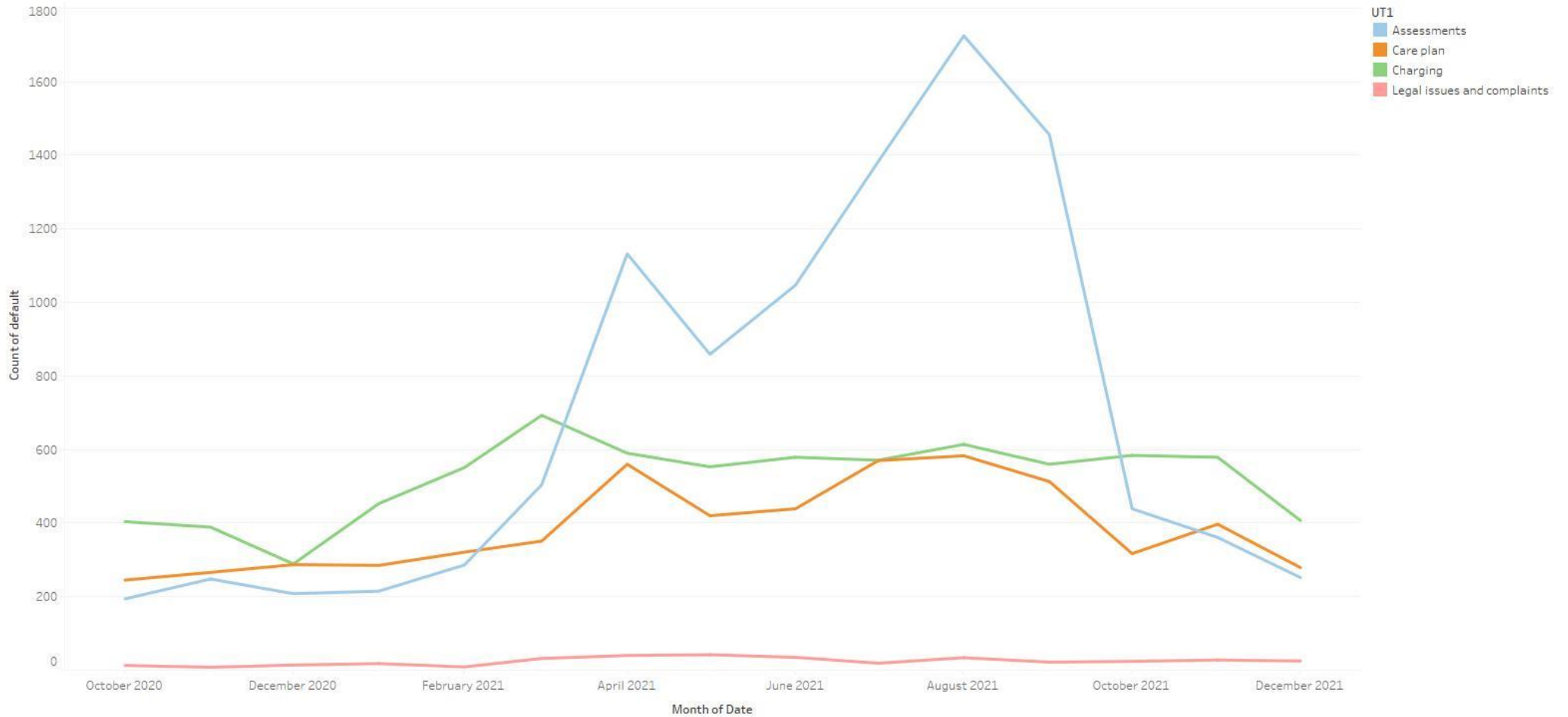
We have welcomed RNIB to our project this year and include them in this analysis of trends per quarter, looking at specifically October to December 2020 compared with October to December 2021.

We look at four key themes as a snapshot of data during the outset of the pandemic and into 2021: assessments, care plans, charging and legal issues / complaints.

Quarterly comparisons

Q4 2020 and Q4 2021

Learning disability, carers, older people and sensory disability



We take a snapshot of data from quarter four (October to December) 2020 and compare this to the same time period of October – December 2021 (below) on four key themes.

Quarterly snapshot insight

61% increase in assessment enquiries

We highlight above in our assessment analysis the concerns about rising demand on the social care system. The situation shows no sign of subsiding in this 2020 and 2021 quarterly snapshot, with a significant 61% increase in assessment queries. We remain hugely concerned that no additional resources or funding has been made available to local authorities for the specific purpose of addressing this huge level of increasing demand.

24% increase in care plan enquiries

Care plan queries continue to feature as a key theme in our quarterly snapshot, with a 24% increase. As the country emerged from national restrictions in June 2021, many people found that their day centres had closed completely, or the care and support that they thought would be there for them after restrictions ended had in fact been suspended.

45% increase in charging queries

In a significant increase from the 4% observed from 2019/20 compared with 2021/22, we note a 45% increase in this 2020 and 2021 quarterly comparison. Within this time period, common issues included: people contacting our members for support challenging a financial assessment which they believed did not take into account appropriate disability related expenditure; requests for support in finding out local authority rules on charging; requests for information about capital limits and charging in a residential care setting; and requests for information on mandatory disregards in financial assessments.

With new rules coming into force in 2023 as described in our 2019/20 – 2021/22 analysis, we will continue to monitor the impact on demand for advice within our member groups.

120% increase in legal issues and complaints

We will monitor this issue into the next quarter of our project, and draw in any findings or reflections from other areas of Access Social Care's work, but this is concerning given the finding of our Career Pathway report mentioned above, which clearly shows that despite the demand being there for specialist legal advice, there is a major issue with supply²⁴.

²⁴ [Community Care Legal Career Pathways Research Report \(accesscharity.org.uk\)](https://www.accesscharity.org.uk/research-reports/community-care-legal-career-pathways-research-report) and ['Loss-making' Rates Behind Decline in Community Care Work \(accesscharity.org.uk\)](https://www.accesscharity.org.uk/research-reports/loss-making-rates-behind-decline-in-community-care-work)

Reflections and next steps

Our first State of the Nation report published in May 2021 was published while the UK remained under an element of COVID-19 restrictions, which were not lifted until June 2021. The early impact of the pandemic on key social care advice trends was not yet known.

This year, we note several worrying trends. Needs assessments are the gateway to care and support and can be an intervention in their own right. It is concerning that advice demand and provision for this key legal process is increasing, with many reporting delays or even refusals of assessment.

We also see growing concern around key elements of the care planning process which are vital for the successful provision of care and support: delays to care plan reviews, refusals of support, and chronic staff shortages leaving many without the care they need. We described the changes coming in 2023 which will bring self-funders into the social care system to benefit from the lifetime cap. We outline in greater detail our concerns around the volume of people awaiting assessments in our Supporting Local Implementation²⁵ consultation response, including concern over lack of mandatory training for those carrying out outsourced needs assessments.

These developments are set against an ongoing backdrop of ever decreasing adult social care budgets. Access Social Care has been carrying out research into local authority budgets and the challenges faced across the country for local authorities delivering services in challenging financial circumstances. Savings targets for adult social care are common, with local authorities in England identifying at least £48m of adult social care savings targets in 2021/22 alone. Our organisation is continuing to monitor adult social care savings and efficiencies into 2022/23.

We are all aware of a pre-existing level of unmet advice demand – we may have seen some of this addressed in the 2020/21 COVID-19 response, but many emerging issues continue to increase in enquiry volume despite the immediate COVID-19 response having passed. Our Helplines Group Data Collaboration project will continue into 2022/23, taking routine three monthly intakes of data.

We are welcoming new organisations to the project – please contact the author of this report with any questions on the contents of this report, or on joining our project, at Hannah.Hewish@accesscharity.org.uk



²⁵ [Access Social Care responds to consultation on 'Supporting local preparation – draft guidance' \(accesscharity.org.uk\)](https://www.accesscharity.org.uk/access-social-care-responds-to-consultation-on-supporting-local-preparation-draft-guidance/)

Annex A

Universal themes:

Theme	Name	Definition
Universal theme 1	Advocacy	Formal support to help a person navigate the care assessment and planning process
Universal theme 2	Information seeking	Contacts to helplines encompassing a range of questions about rights
Universal theme 3	Assessment	A Care Act 2014 assessment of care and support needs for a disabled person. A precursor to receiving support, or an increase in support.
Universal theme 4	Care plans	Sets out the support needed to meet a person's eligible care and support needs (as identified first in an assessment of need)
Universal theme 5	Carers	Contacts to helplines from carers (or family or friends of carers) with questions about being or becoming a carer
Universal theme 6	Charging concerns	Social care charges, calculated after a needs assessment and care plan has been finalised, are assessed via a financial assessment. This looks at a person's income and expenditure and determines the amount of money they will have in their personal budget to fund support.
Universal theme 7	Direct payments	A person can choose to have their personal budget paid directly to them, or a third party, to commission their own support rather than the local authority doing this for them.
Universal theme 8	Cuts to packages	Changes or reductions made to a person's existing package of care and support.
Universal theme 10	Funding disputes	After it has been established that a person has eligible care and support needs, there can be disputes over who is the correct authority to fund this care and support. This might be based on where a person lives, or has recently moved from for example.
Universal theme 11	Mental capacity	All contacts about mental capacity related issues in the context of community care decision making.
Universal theme 12	Safeguarding	Concerns raised over the health, safety, or wellbeing of a disabled or vulnerable person.
Universal theme 13	Legal issues and complaints	Contacts where a legal issue or complaint has been directly mentioned. People receiving care and support may not know that their issue is a legal issue on contacting a helpline, and so these contacts appear relatively low. In fact, a large number of the queries received by helplines relate to legal issues most commonly within the Care Act 2014.
Universal theme 14	COVID-19	Contacts to helplines relating directly to the COVID-19 pandemic, such as problems visiting a loved one in care homes or supported living, or access to priority vaccination as an unpaid carer.

Annex B – Process

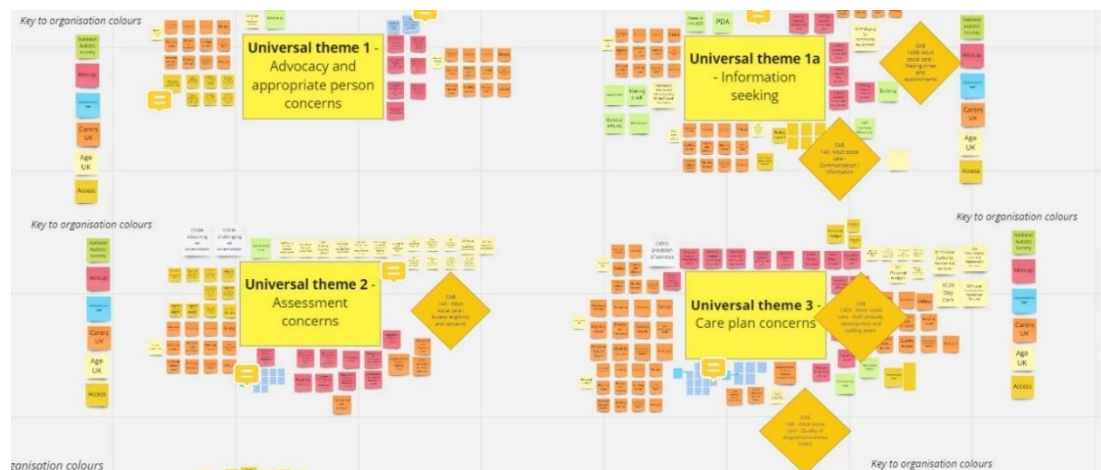
All group members provide information and advice on broadly similar issues, but are recording their data in different ways using different categorisation methods. We studied each group member’s internal method of categorising calls and emails into their helplines. This broadly resembled two ‘tiers’ of data collection, within a primary *community care* categorisation.

Example

Community care	Assessments	Information about adult assessments
		Delay in getting assessment
		No appropriate person / advocate
		Concern around quality of assessment

Based on this analysis, we drafted a set of **universal themes** which we proposed could appropriately reflect most data collected by each group member. We convened a ‘universal themes’ workshop in July 2020, facilitated online and attended by the data leads from each group member. The aim was to collaborate with group members to co-produce a final set of universal themes which would accurately reflect each group member’s data. This was a successful half-day interactive workshop. We hosted it using an online visual collaboration platform, Miro, so that each group member could log in, navigate, and edit the board in real time:

Workshop screenshot



We concluded the workshop with an agreed set of universal themes, at two 'tiers' (Universal Theme 1, for example 'Assessments', would have a Universal Theme 2 within it such as 'Refusal to carry out an assessment'). All incoming datasets could be mapped against these themes, and we created a mapping document to be used in the data processing pipeline.

Data Processing

In phase one, the pilot study, we processed 7,000 separate contacts (each an individual enquiry). During phase two, we grew the project to 25,000 lines of data. Thanks to support from the Royal Mencap Society, we used the software KNIME, free and open-source data analytics, reporting and integration platform to build a bespoke pipeline that prepares the universal dataset. This report is based on over 74,000 separate contacts, covering April 2019- March 2022.

Each individual organisation sent a spreadsheet to us containing:

- Date of enquiry
- Tier 1 code
- Tier 2 code
- Tier 3 code
- Local Authority (if available)

The pipeline extracts the data from each organisation's spreadsheet and cleanses the data for consistency, for example to ensure that the date format is recorded in the same way across all data. We then add the universal themes by mapping them to the organisations tier code and, where possible, add local authority data and ONS geographic codes. We then output a cleansed and consistent dataset of all organisations. Any codes or local authorities that we cannot join are outputted to a different file, this allows us to update codes within the pipeline that may have changed at an organisation, and re-match them to the universal system and re-run the pipeline.