

# **Missing millions**

**Exploring hidden and  
unmet social care need  
for disabled people**

**July 2024**

# Contents

Contents.....	1
Executive summary.....	2
Endorsements.....	4
Introduction.....	5
Methodology.....	7
Findings.....	9
Conclusions.....	17
Recommendations.....	18
Detailed methodology.....	25

# Executive summary

## Headline findings

Our new research reveals social care support can be transformative for those who receive it. It can support disabled people to do tasks they would otherwise struggle to do, like cleaning, eating, working, socialising, and staying active.

However, extrapolating our survey data to national level data, we found that as many as 1.5 million working-age disabled people in England are not receiving social care support, despite potentially being eligible for care.

It is unknown how many of this group would formally qualify for public-funded care, joining the 300,000 disabled people who had long-term care paid for by their council in 2022/23. However, our research highlights that too many people are going without support that could help them.

Our report focuses on the positive impact and benefits of good social care on people's lives, alongside challenges facing the social care system, including hidden demand, unmet need, and under-met need. For this report, we are using the following definitions:

- Hidden demand – potential unmet social care needs under the Care Act.
- Unmet need – any other needs going unsupported, including daily living activities that don't meet Care Act eligibility criteria.

## This report sets out the following findings:

- We estimate that up to 1.5 million disabled adults in England could be eligible for social care or other support but are not receiving it (hidden demand).
- When people receive social care support, their experiences are very positive, with 78% of disabled adults aged 18-64 agreeing that their care helped them live the lives they wanted to.
- Social care helps people stay healthy, do their favourite activities, eat and drink, work and volunteer, and look after themselves and their homes.
- Only 9% of people we spoke to disagreed that care helped them live the lives they wanted to.
- Access to social care remains a challenge. 28% of our total sample had never accessed care, despite self-identifying as eligible. This was due to barriers including:
  - Not knowing where to go for support.
  - Difficulties navigating the care system.
  - Not being able to afford support.

- The closing of local services.
- This figure could be higher if you include a further 10% of our total sample who are not accessing formal care but receiving support from unpaid carers.
  - It would be reasonable to include this group, as three-quarters who access care also noted additional support from an unpaid carer.
- Most people waiting for care assessments received information and support, including how long they could expect to wait for an assessment (32%) and information on what to expect.
- Around 10% of people received no support at all while waiting.

## Key recommendations

Based on this report's findings, we set out the following recommendations for decision-makers, including Government, local authorities, and integrated care systems (ICS):

- The Government must fund local authorities to raise public awareness of social care, improve ways of accessing social care services, and find potentially eligible individuals through proactive outreach and statutory information, advice, and signposting services.
- Funding should be made available to local councils to boost social care capacity and support councils in addressing existing care assessments and care package backlogs.
- Funding should be ringfenced for organisations providing independent advice and guidance related to social care.

In response to broader challenges facing social care, we set out the following recommendations for long-term and funded reforms:

- A fully funded and long-term reform plan for social care addressing:
  - Workforce challenges, including retention, recognition and pay.
  - A focus on prevention of care needs and support to help people live as well and as long as possible in the place they call home.
  - More support for unpaid carers, including reform of [Carer's Allowance](#) and improved access to support for themselves and those they care for.
- Expanded access to [Care Act advocates](#) to support everyone accessing a social care needs assessment.

# Endorsements

“It is so important to shine a light on the experience of people who need social care. This Healthwatch report highlights that what a difference social care makes to people’s lives and wider communities.

“The report also raises some important challenges about unmet need and some solutions including the importance of the Adult Social Care Workforce Strategy. This should focus minds and future action.”

**Sir David Pearson, Co-Chair of the Adult Social Care Workforce Strategy and Chair of TEC Quality**

“It’s positive to hear social care is working well for those people drawing on it, but this report confirms too many disabled people with low level needs are missing out on care and are left to simply ‘get by’, which can risk storing up bigger problems in the future.

“To break this cycle, we need to invest more low level, early support at home and in the community to prevent people reaching crisis point. We agree that key to this is better information and advice about care and support services available to people, which our own Directors say they are struggling to afford to prioritise. We also need a long-term fully funded plan to reform social care and enable people, whatever disability or illness they are facing, to live well, work and care.”

**Anna Hemmings, CEO, Association of Directors of Adult Social Services (ADASS)**

“It’s shocking that as many as 1.5 million working age disabled people in England are missing out on social care, but sadly it’s not surprising.

“As Healthwatch’s reports shows, social care can be transformational for disabled people. Rather than just meeting personal care needs, good social care can enable disabled people to do what’s important to them and live the life they want from socialising, to connecting with others or engaging in leisure activities.

“But [Sense’s own research](#) found that one in five people with complex disabilities don’t feel they have the support they need. And worryingly of people with complex disabilities who receive social care, a quarter told us they’d had their care provision cut in the past year.

“It’s vital that the Government acts now to fix the social care crisis by agreeing a long-term funding plan for social care and introducing a workforce strategy that ensures good quality provision and care for all disabled people.”

**Harriet Edwards, Head of Policy, Public Affairs and Research, Sense**

# Introduction

## What is adult social care?

Adult social care provides vital support for older people and disabled adults who require assistance to live their lives the way they want to.

In 2022/23, [almost one million](#) people in England received publicly funded long-term social care packages. This includes 300,000 disabled adults. Care packages are organised by local authorities, who provide services, fund individuals to arrange their own care, or outsource services to local providers.

Most commonly, people access social care by contacting their local council for a free needs assessment, or receive an NHS referral after being discharged from hospital. Depending on the outcome of a financial assessment, councils will either fully or part fund a person's care package, or people can pay for their care privately.

## Challenges in social care

Social care in England is under financial strain, facing a workforce crisis and [requiring major reform](#).

Other challenges mean people who may benefit from support face barriers to accessing care. [Under the Care Act](#), councils have a responsibility to provide information and advice services to make communities aware of local support and direct people to different types of care.

However, in 2023 the Association of Directors of Adult Social Services (ADASS) [reported](#) that one in four Council Directors were not confident of meeting this statutory information and advice duty.

This leaves people unsure where to turn for social care support, a finding backed up by [recent Healthwatch research](#), which found that people are as likely to visit their GP for advice on social care as their local authority.

The 2023 ADASS Spring Survey also reported that nearly 500,000 people were waiting for their social care needs assessment, care review, or direct payments to begin, and referrals related to carer burnout had increased by 68%.

## What are the aims of this research?

The latest official proposals for social care reform came in a 2021 Government white paper: [People at the Heart of Care](#).

This set out a ten-year reform plan, with an accompanying awareness-raising campaign, plans to fund pilots for more proactive information, advice and signposting services, and the headline policy of a cap on lifetime care costs, a move that is currently paused.

In its chapter on access, the white paper noted that:

“There is a lack of data and evidence on the extent to which care needs are not being met...We believe that better-quality data, including client-level data, will help us to:

- Understand more about who accesses care, how and with what impact.
- Better understand who is not accessing care.
- Better understand how much barriers or choices (or a mix of both) may be a cause of this.”

Our research addresses the lack of data highlighted in the white paper. Specifically, we have set out to provide evidence to these three key questions: **who is accessing care, who isn't, and why?**

Current data only provides some of these answers, and throws up essential questions on unmet social care needs and hidden demand for support. For example, [around 300,000 working-age adults received publicly funded care packages in 2022/23](#), with 600,000 total requests for support. Both figures represent a small proportion of the 5.4 million<sup>1</sup> people in England aged 18-64 with a disability.

However, the definition of disability under the [Equality Act 2010](#) shares similarities with the Care Act's own [eligibility criteria](#) for social care. Both describe physical or mental impairments that negatively affect an individual's ability to perform tasks.

The extent to which eligibility might apply to disabled people who have had no interaction with social care services is unknown. Though [Age UK](#) has estimated that 2.6 million people aged 50+ in England have an unmet need for care, there are no national estimates of unmet need for working-age adults.

We believe that creating this estimate while also seeking to understand the barriers to and experiences of care will be a valuable contribution to social care reform plans.

---

<sup>1</sup> Savanta estimate for Healthwatch England, based on ONS estimates of economic activity of people aged 18-64.

# Methodology

Our survey was carried out online by Savanta between February and March 2024. We surveyed a representative sample of 1,504 disabled adults aged 18 to 64. We are confident in our approach; however, we are also conscious that there are some important caveats to note when considering our findings:

- While our questions have reflected the wording on social care eligibility set out in the Care Act, answering questions in a survey differs from having a formal care needs assessment. Therefore, when we present figures for how many people may be eligible for social care but are not accessing it, we are not asserting that they would all receive it if they applied. Instead, we present estimates for need: how many people *may* be eligible.
- Our survey is only focused on care needs. Financial eligibility is a separate issue, and we have not considered this. There will be people within our sample who may be eligible for social care, determined by a needs assessment, but would not receive local authority-funded social care in practice because of their financial situation. No public spending assumptions should be drawn from this survey.
- Because of the online format of our survey, a section of the disabled population will be unrepresented in this research, either because they are not online or because they would otherwise find it too challenging to take this survey.

***Savanta interviewed 1,504 working-age disabled adults (18-65) in England between February 22, 2024, and March 7, 2024. The data was weighted to be nationally representative of working-age disabled adults in the UK by age, gender, and region, based on ONS Estimates of the economic activity of those aged 18-64 with a disability. Based on the most recent estimates, there are approximately 5.4 million working-age adults with a disability in England.***

***The interviews were completed online with Savanta's survey platform. This has been tested based on the Web Content Accessibility Guidelines (WCAG 2.1) conformance levels and is rated as level AA compliant. In other words, the surveys are rendered to maximise accessibility to those who may otherwise be disadvantaged – for example, being compatible***



*with screen readers for those with visual impairment with the questions designed to be as simple as possible for participants to understand.*

*Researchers checked data at regular intervals using various methods to ensure that respondents' answers were logical and accurate and that, as far as possible, it was clear that respondents had understood the survey.*

*While these important steps have been taken to ensure the survey is accessible and our sample is as representative as possible, we note that definitions of care can be complex and contain areas of subjective judgements that can be interpreted differently. In addition, as the survey was conducted online – this may impact complete representativeness in some cases.*

*As such, we recognise that these findings are an exploration of the views of an audience and, while robust, may not extrapolate perfectly to the whole working-age disabled adult population.*

# Findings

## Social care support can be life changing.

### Experiences of social care support

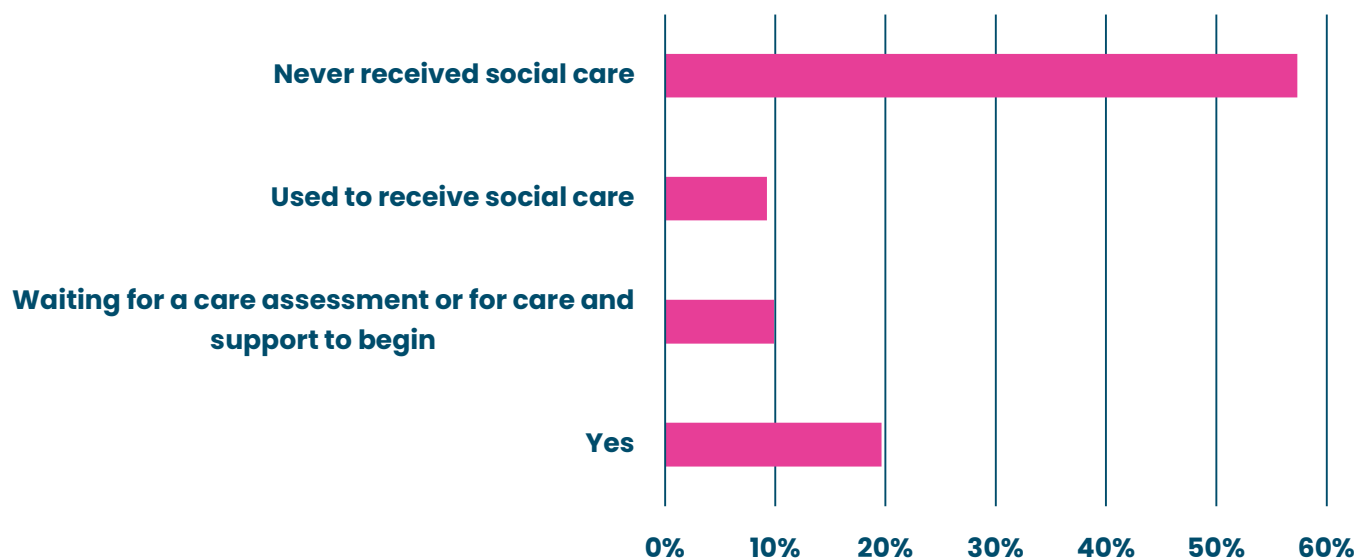
We found that most people receiving care have positive experiences and that their care is working as intended: supporting people to live the lives they want to live.

Over three-quarters of people currently receiving care think it helps them live the life they want to live (35% of people currently receiving care 'somewhat agree' with that statement and 43% 'strongly agree'). This compares to only 6% who somewhat disagree and 3% who strongly disagree.



We found that a substantial majority of working-age disabled adults are not currently receiving social care. 57% have never received social care, a further 10% are currently waiting for a care assessment or for care to start, and 9% used to receive social care but don't anymore. This means just over three-quarters of working-age disabled adults are not currently accessing social care, compared to a fifth (20%) who are.

### Do you currently receive any social care support?



A fifth of the working-age disabled adult population in England would represent just over a million people. However, figures from the NHS suggest that only around 300,000 working-age disabled people are receiving care from their local council.<sup>2</sup> While those accessing care are therefore over-represented in our sample, our figures also include those receiving private care and a greater range of care and support (particularly emergency care, adaptations, and community support) than is reflected in official data.

This over-representation may have contributed to a smaller headline estimate on social care demand, outlined in the next section of the report. However, it provided a larger sample to understand how people feel about the care they receive.

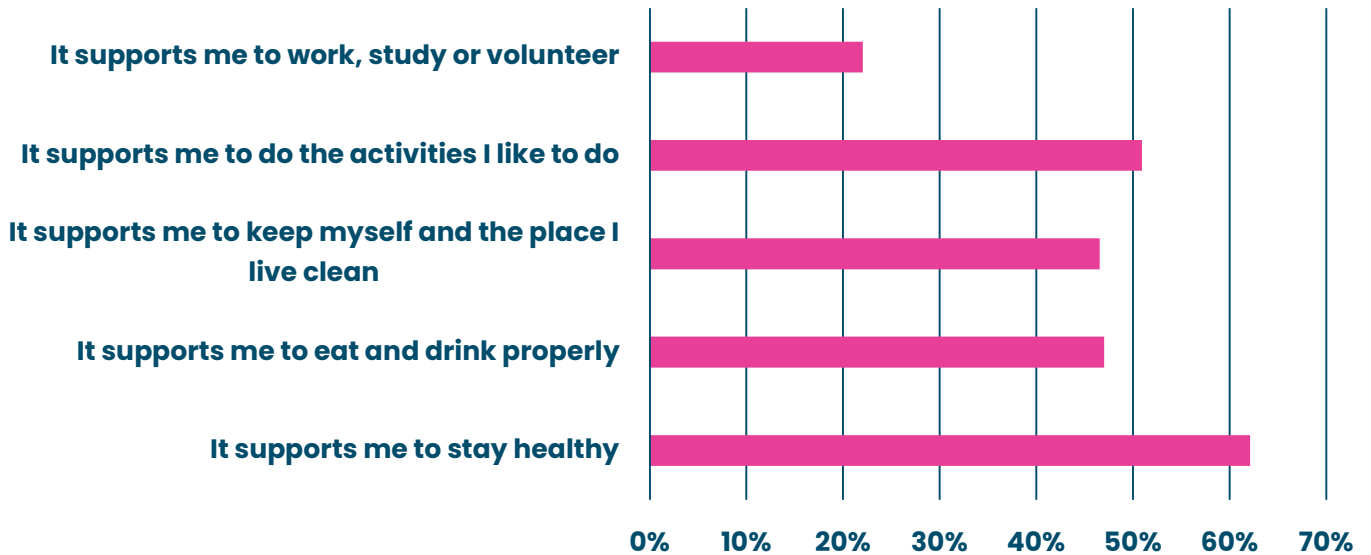
Although we identify areas for improvement throughout this report, particularly concerning access, there is a positive message here: when people do get care, they generally feel optimistic about it. Because care can be so life-changing, our headline figure of hidden demand and unmet need is so important.

We also asked people who receive care what that care helps them to do. We found that nearly two-thirds (62%) of people receiving care say it helps them stay healthy, while half (51%) say it helps them do the activities they like. Just under half (47% in both cases) said their care enables them to keep themselves and their home clean, and supports them to eat and drink properly. A lower

<sup>2</sup> [Adult Social Care Activity and Finance Report, England, 2022-23 - NHS England Digital](#)

number, 22% of people, said their care supports them in working, studying, or volunteering.

### What does the support you receive enable you to do?



One notable demographic difference is the much higher figure of 'keep myself and the place I live clean' among 55-to-64-year-olds. The overall figure for this is 47%; however, for people over 55, it is 73%. This suggests an increasing need for this type of support as people get older, highlighting why it's important that the care and support people receive adapts as their needs change.

### Access must be improved.

#### Who isn't accessing care?

Having examined one of the white paper questions, 'Who is accessing care?', this section examines 'who isn't accessing care?' – the hidden demand for care.

To generate an estimate of potential hidden demand and subsequent unmet need, we asked Savanta to provide data splits that specifically highlight people who may be eligible for social care but have never accessed it. We also recognise that not everyone who has never accessed social care is necessarily eligible for – or wants – formal care and support.

28% of our total sample of 1,504 working-age disabled adults fit this definition for hidden demand and unmet need. This represents up to 1.5 million working-age adults in England. Savanta created this figure for us by calculating the number of respondents who meet two criteria:

- 1) Self-identifying as eligible for social care under the Care Act.
- 2) Never having received social care due to the following reasons:

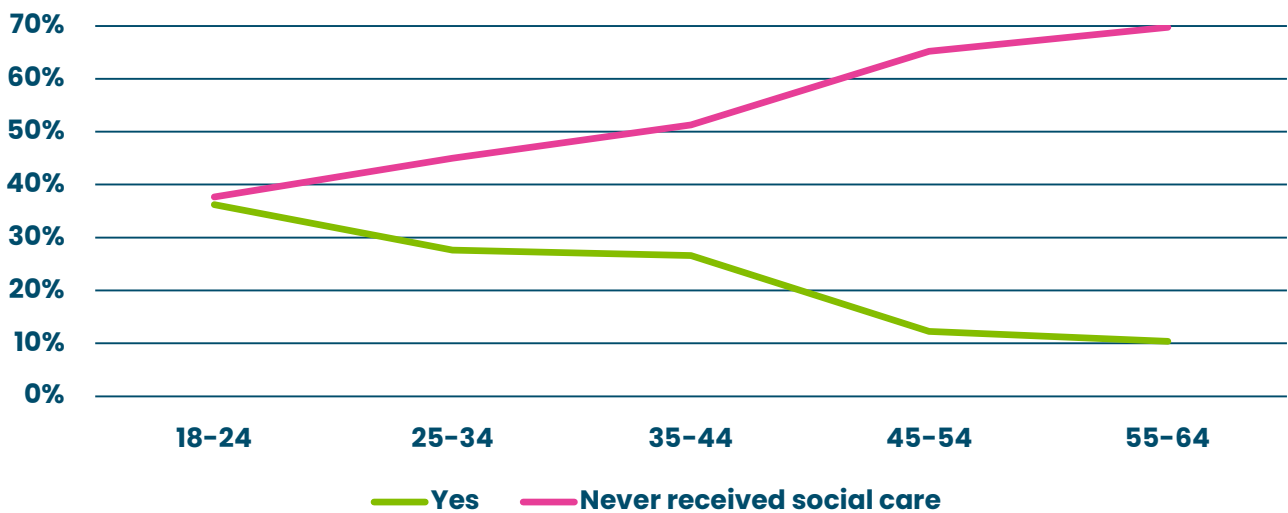
- Not knowing where to go for support (34%).
- Not thinking they could get any support (65%).
- Not being able to afford to pay for care or contributions (26%).
- Finding it too difficult to get support from councils or the NHS (14%).
- The closing of local services (2%).

This estimate excluded people who had previously accessed care, those who did not want help, those who were accessing state benefits, those who told us they were ineligible for support, and those receiving unpaid support.

Please see the Appendix at the end of the report for more details on the survey questions we asked of participants and how we arrived at this estimate.

Our results also show that the difference between the number of people accessing social care and those who have never accessed social care increases substantially with age.

### Do you currently receive any social care support?



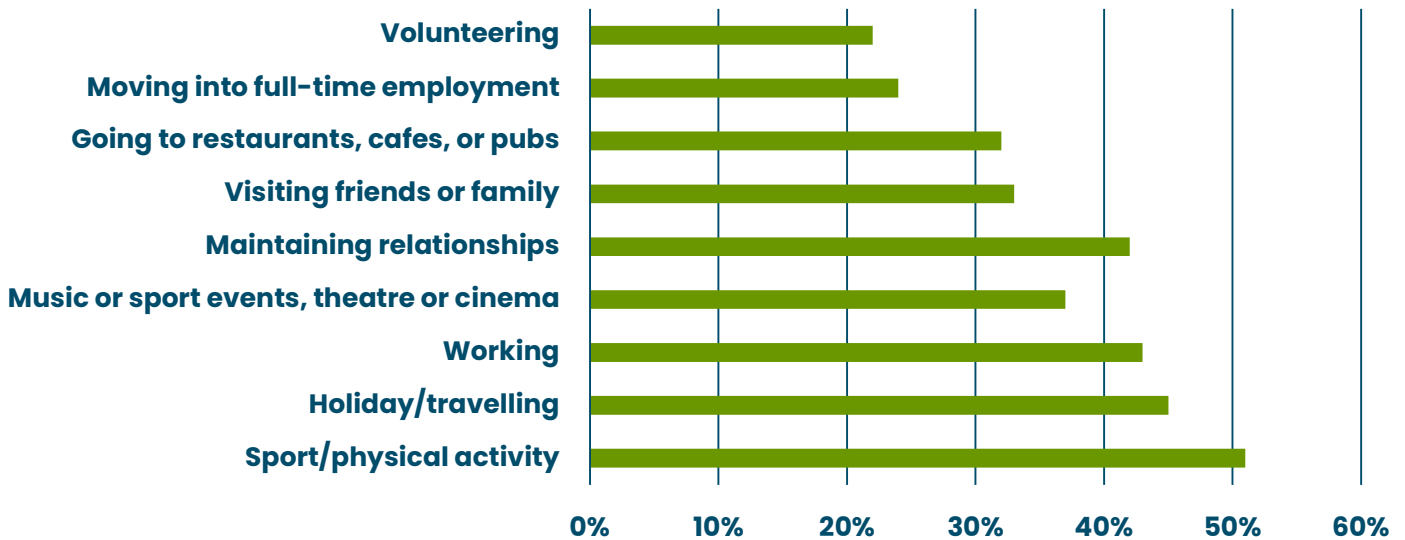
### How could social care help?

As well as assessing people’s needs, social care assessments also consider what outcomes individuals are hoping to get. To understand how social care could improve lives, we asked people what they would like to be able to do but cannot because of their disability.

To answer this question, we will look at our 'hidden demand' group—the 28% of people who do not receive care but may be eligible under the Care Act.

Notably, sport or physical activity is the only option that over half of people selected; 51%. Less than a fifth of people selected none of the options. This demonstrates that there is quite a wide variety of things people would like help to be able to do.

### Those not receiving care: what would you like to be able to do but cannot due to your disability?



The things people would like to be able to do are diverse, and support should be flexible and personalised to reflect this.

These figures also underline that people would like to be able to do everyday things. About a third want to go to restaurants, cafes, and pubs (32%) or visit friends or family (33%). 37% want to go to music or sports events, the theatre or cinema. 42% want to maintain relationships with friends and family.

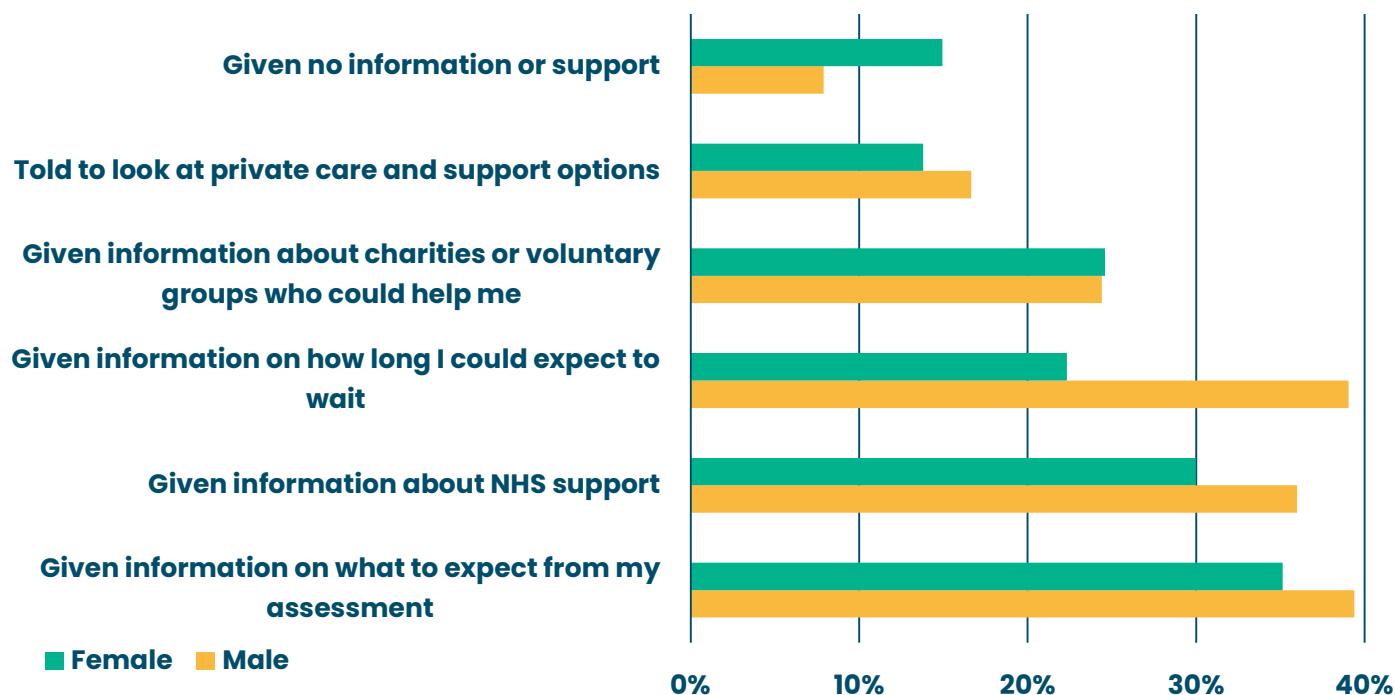
Supporting people to do some of these things is where social care could make a significant difference to those who currently do not receive it.

### Experiences of waiting for care assessments

We asked people what happened while waiting for a social care assessment or for their support to begin. Over a third (37%) received information on what to expect from their assessment, 33% stated they were given information about NHS support, and 32% said they were given information on how long they could expect to wait. Worryingly, we found that 11% of people were not given any information or support.

We also found that men were more likely to say they were given information on what to expect from their assessment, information about NHS support, and information on how long they could expect to wait compared to women. Women were more likely to say they were not given any information or support.

### While you were waiting for a social care assessment or support to begin, which, if any, of the following happened?



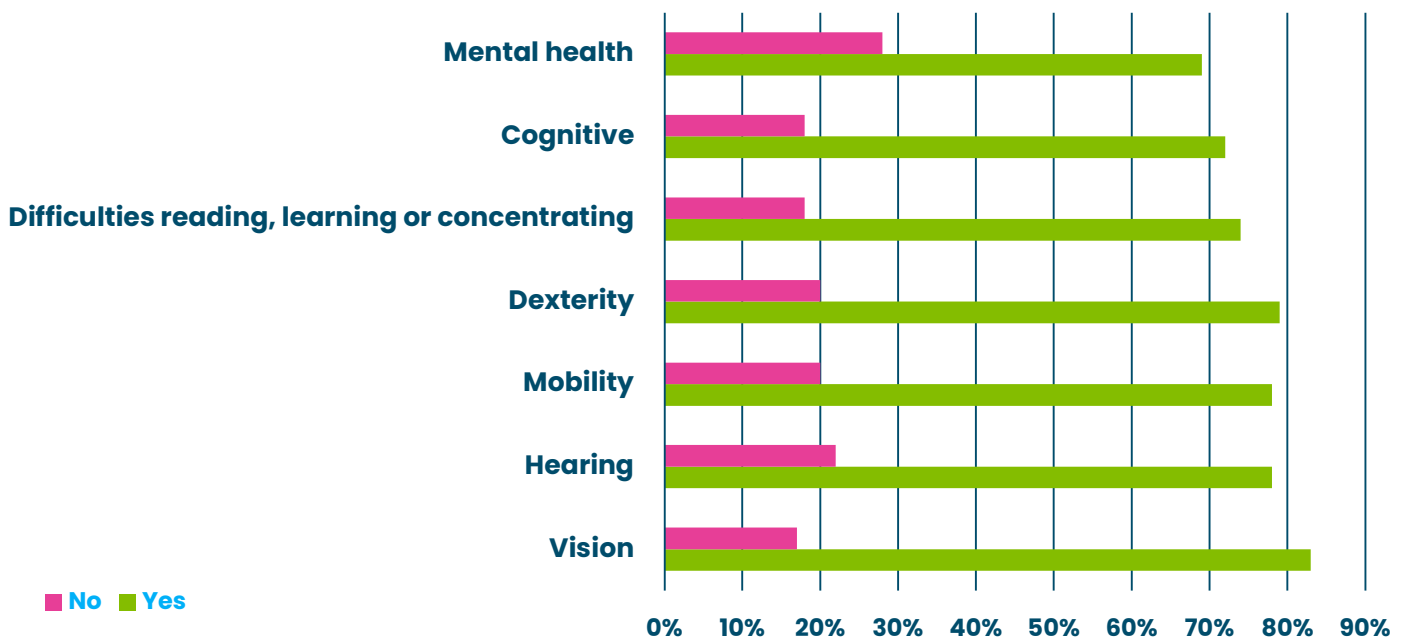
People with higher incomes also reported receiving more support and information while they waited for care. Over a third, or 35%, of people earning less than £30,000 said they were given information on what to expect from their assessment, compared to 60% of people earning more than £70,000. 13% of people earning less than £30,000 said they had not been given any information or support, compared to only 3% of those earning more than £70,000.

### Reliance on unpaid support

Overall, we found that 73% of respondents accessing care also receive unpaid support from a friend or family member. Our results show significant differences depending on the type of impairment people have.

For example, those with a mental health condition are less likely to receive support from a friend or family member, with 69% saying they receive unpaid care, whereas 83% of people with a disability that affects their vision are receiving unpaid support in addition to formal social care support.

## 'Do you also receive support from a friend or family member as an unpaid carer?' Split by type of disability

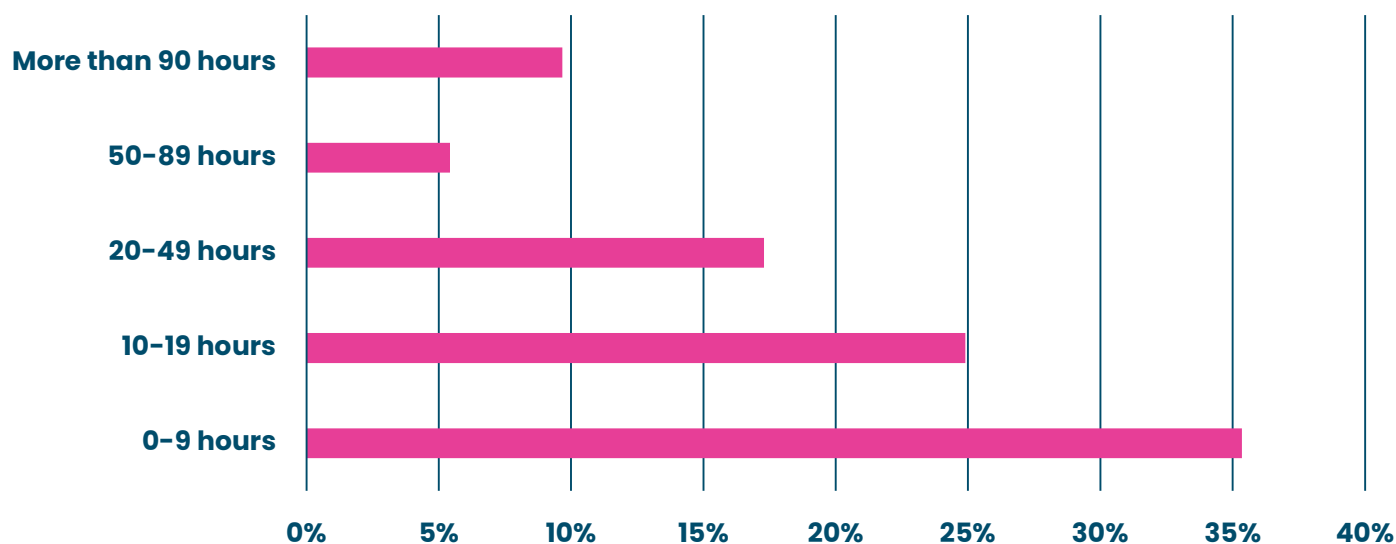


We also found that receiving unpaid care from a friend or family member was the primary reason people had never received formal social care support, with 44% citing this as a reason. Even among those who used to receive social care but no longer do, receiving support from a friend or family member was still a significant factor in why they stopped accessing support, with almost one-fifth of people, 18%, naming this as a reason. Only using state benefits, like Personal Independence Payments (PIP), to meet their needs instead was named by more people (30%) as a reason for no longer receiving social care support.



To give greater context to our findings on the levels of support provided by unpaid carers, we asked those who said they received support how many hours of support unpaid carers provide on average per week. Notably, we found that a majority receive under 20 hours, but around one in three people with unpaid carers received over 20 hours of unpaid care a week. 5% receive unpaid care for 50 to 89 hours per week, and 10% receive support for more than 90 hours per week.

### Average hours of support provided by unpaid carers per week



The role of unpaid care nationally is significant. [Census data](#) from 2021 indicated that around 8.8% of people in England provided unpaid care, with the burden falling disproportionately on women.

# Conclusions

Our research shows that social care support is transforming the lives of those who receive it, with 78% of people with access to care speaking positively about the help they have received. This includes support that helps people to learn, to work, to socialise, and to live the lives they want to live.

However, our headline finding that **up to 1.5 million** working-age disabled people in England may be missing out on social care or other support is a clear call to action to policymakers: England's social care system needs immediate resources to meet the needs of our population.

If our estimate was converted to requests for support, this would double the new clients for whom an outcome was determined in 2022-23. This will clearly be a huge challenge, given the council pressures and the declining confidence of council leaders to meet their statutory duties.

But it is vital that disabled people know about the types of support available to them – and so it is equally vital that local authorities are resourced to do all they can to proactively reach out to people in their areas.

We have been clear that our evidence should not be misinterpreted as suggesting that 1.5 million more people should receive publicly funded care services. Some of this group may not be eligible, while others will require signposting to non-formal care support. Others could be self-funders or not want any help. Ultimately, only a care assessment can make robust decisions on formal needs.

But our research clearly shows that far too many disabled people are facing challenges, and not being supported to live the lives they want to.

Looking ahead, we believe a funded and reformed social care system must increase its focus on prevention and provide a more diverse set of support options to help disabled people achieve their goals. Services like social prescribing and community support can help reduce and manage people's needs.

Action must also be taken to address the under-met need for those whose care packages are not delivering care as intended. And given the hours of unpaid care provided across the country, immediate support must be provided for unpaid carers and those they care for.

Our recommendations will require additional resources to deliver. However, we should consider the economic and health costs of people's unmet or under-met needs. These include additional NHS costs, higher unemployment, and pressures on unpaid carers.

As part of a broader campaign on social care reform, Healthwatch England looks forward to working with decision-makers and those across the health and care sector to improve people's experiences of services.

# Recommendations

## Funding to address the hidden demand for care and support

In the longer term, a lasting vision for reform is needed. However, immediate access barriers must be addressed, and services must be supported to understand hidden demand in their area.

What we're calling for	Why this is needed	How to make this happen	Who should be involved
Funding to tackle social care assessment, review, and care package backlogs.	<p>According to ADASS, in autumn 2023, nearly a quarter of a million people were waiting for a care assessment.</p> <p>It vital that people are supported while waiting for care. Though many had access to information and signposting, one in ten received no information at all.</p> <p>And despite a large majority agreeing that social care changed their lives for the better, one in ten people still experienced under-met needs.</p> <p>Ensuring these individuals have access to regular reviews of their care is also essential.</p>	<p>Through the annual local government finance settlement (LGFS), Government should provide councils with ringfenced capacity funds.</p> <p>Councils could then use this funding to employ additional social workers and care managers, as well as additional package purchases.</p> <p>People waiting for assessments must also have a point of contact in their council and should not feel forgotten.</p> <p>Other support while waiting for assessments should be coproduced at Place-level with local people, health services, and the voluntary sector.</p>	<p>Government</p> <p>Local Authorities</p> <p>VCSE sector</p>
Funding and action to improve public awareness of social care through	We estimate that around 1.5 million people could be eligible for some level of support but have	More support through the LGFS would give Councils the resources they need to proactively reach out to people	Department of Health and Social Care

<p>proactive local authority information, advice, and signposting services.</p>	<p>never interacted with social care services.</p> <p>Around a third of people who may have Care Act eligible needs told us they didn't think they could get support for their needs.</p> <p>And combined with previous Healthwatch research into understanding of social care, we know people don't always know where to turn for support.</p> <p>Not everyone will be eligible for publicly funded care, but where they are, legislation clearly states that they should be able to access care.</p>	<p>who may be eligible for support. This must include people with no current paid or unpaid support.</p> <p>Reaching a broader range of individuals can be achieved through proactive pre-assessments or screening of social care need at Place-level.</p> <p>The Partners in Care and Health <a href="#">adult social care information and advice toolkit</a> provides self-improvement tools and key themes that can help councils meet their statutory requirements in a coproduced and proactive way.</p> <p>As well as an increase in formal care needs assessments, this may also result in better signposting to other care and support options, contributing to a more preventative approach.</p>	<p>Local Authorities</p> <p>Integrated Care Systems</p>
<p>Independent advice and guidance funding to be ringfenced and returned to sustainable levels.</p>	<p>Healthwatch England and the local Healthwatch network have a statutory duty to deliver information, advice, and signposting services.</p> <p>And according to our research, one in four people waiting for an assessment are</p>	<p>There needs to be greater investment in independent social care advice and signposting services whose funding has been impacted in recent years.</p> <p>For example, local Healthwatch</p>	<p>Government</p> <p>Local Authority Commissioners</p> <p>Healthwatch England</p> <p>Local Healthwatch</p>

	signposted to local voluntary organisations.	services that support 1 million people every year with advice and information has seen its funding fall by 43% in real terms since 2013/14.	VCSE sector
Funding to ensure safe hospital discharge and delivery of appropriate short-term care packages.	<p><a href="#">Healthwatch research</a> has shown poor experiences of hospital discharge processes.</p> <p>This includes unpaid carers feeling unprepared to support the person they care for at the point of discharge.</p> <p>Improved hospital discharge processes, including more social care resources to provide short-term care packages, are vital to easing pressures across ICSs.</p>	<p>Through the Better Care Fund, health and care leaders work together to support people discharged from hospital.</p> <p>These arrangements often focus on freeing up hospital capacity, but a renewed focus on social care capacity is vital.</p> <p>Capturing data on health deterioration over seven and thirty days would help decision-makers understand where processes are not always working for people, as well as for services.</p> <p>This should include data on support at home, readmissions, emergency readmissions, death after discharge, and contact with another service about the same issue.</p>	<p>Government</p> <p>Local Authorities</p> <p>Integrated Care Systems</p> <p>NHS England</p>

### Longer-term reform of social care

While this research focuses on hidden demand and unmet need, social care's broader challenges are impossible to ignore. We are calling for funded long-term reform of social care to include the elements listed below.

Any national reform of social care must involve people who draw on care or provide it informally for someone they know.

What we're calling for	Why this is needed	How to make this happen	Who should be involved
<p>An official calculation of adult social care need and inequality in care access.</p>	<p>Our work, alongside Age UK's work with older adults, shows the need for a comprehensive assessment of the public's need for adult social care and other types of support.</p> <p>This must include formal definition of different types of unmet need, along with recognition of inequalities that exist in access to social care and alternative sources of support that people draw on.</p>	<p>The Department of Health and Care should lead this calculation.</p> <p>Healthwatch England and the local Healthwatch network would support the process.</p> <p>This will support people who may benefit from formal social care and help decision-makers rethink how different types of support are assessed and delivered in our communities.</p> <p>The Government should also consider introducing 'need for care' in the next iteration of the Family Resources Survey or other comprehensive survey.</p>	<p>Government</p> <p>Healthwatch England</p> <p>Local Healthwatch</p> <p>Integrated Care Systems</p> <p>Local Authorities</p> <p>Social Care Charities</p> <p>Social Care Providers</p> <p>Care Quality Commission</p>
<p>A more preventative and community-based social care system</p>	<p>The level of unmet need that we have identified requires social care to work in a very different way.</p> <p>Social care systems must be supported to promote healthy and resilient communities that reduce need through preventative investments, such as in community wellbeing programmes and</p>	<p>Comprehensive social care reform must provide sufficient long-term funding to allow systems to invest in prevention, not simply react to need.</p> <p>This funding should be used by councils to work with local people and the VCSE sector to co-design</p>	<p>Government</p> <p>Integrated Care Systems</p> <p>Local Authorities</p> <p>Social Care Providers</p> <p>VCSE sector</p>

	accessible housing, not just formal care delivery.	services that work for them.	
More support for unpaid carers and reform of Carer's Allowance.	<p>Unpaid carers are increasingly delivering more care and requiring more support themselves.</p> <p>We cannot allow unpaid carers to prop up and cover for underfunding of social care.</p>	<p>Proactive outreach from councils must extend to unpaid carers, to ensure they understand their rights and have access to the support they need, including personalised breaks.</p> <p>Carer's Allowance should also be reformed, including:</p> <ul style="list-style-type: none"> <li>• Increasing total benefit provided.</li> <li>• Access to more funding for those caring for multiple people.</li> <li>• Moving from an earnings limit to an hours-of-work limit.</li> <li>• Scrapping the 21-hours rule for those in full-time education.</li> <li>• Allowing more than one carer to claim for the caring responsibilities of an individual.</li> </ul>	<p>Government</p> <p>Local Authorities</p> <p>Carer Charities</p>
A long-term funded social	Our findings show a larger and more empowered social	The government must recognise, fund, and implement	Government Skills for Care

<p>care workforce strategy</p>	<p>care workforce is required to tackle unmet need.</p> <p><u>Skills for Care's</u> workforce data shows that despite recent improvements, turnover rates remain high across social care, with over 150,000 vacant posts.</p> <p>The impact is growing pressures on existing staff to manage demand.</p> <p>The delivery of truly personalised care is also put at risk, with high turnover rates affecting relationships between care workers and those receiving care.</p>	<p>Skills for Care's 15-year adult social care workforce strategy.</p>	<p>Local Authorities</p> <p>Integrated Care Systems</p> <p>Social Care Providers</p>
<p>Expanded access to Care Act advocates.</p>	<p>The Care Act provides a legal right to people who need support to understand decisions about their care and support.</p> <p>Given the complexities of our social care system, more people could benefit from this advocacy. This would give people going through assessments the confidence that their needs are being properly communicated and outcomes and decisions are coproduced.</p>	<p>Amend the Care Act through a statutory instrument to state that advocates should be offered to every individual ahead of their care needs assessment.</p> <p>Widening this offer to benefit more people will require additional resources and joint working between councils and local voluntary and advocacy teams.</p> <p>Access should remain a guarantee for those who experience difficulties understanding, retaining or using</p>	<p>Government</p> <p>Local Authorities</p> <p>VCSE sector</p>



		information relayed during a care assessment.	
--	--	---	--

# Detailed methodology

The goal of this research is to understand the experiences of, and attitudes towards, social care among working-age disabled adults. To do this, we commissioned polling from Savanta. We tasked Savanta with creating a sample representative of the population of working-age disabled people in England, and we worked with them to ensure we were happy with the sample.

## Considerations of our methodology

Creating such a sample presents some difficulties. The main challenge is determining how to make the sample representative enough to allow us to feel confident extrapolating findings to the whole working-age disabled population of England.

We commissioned Savanta in part because of its previous work in this area, including creating a nationally representative sample of working-age disabled adults for another client.<sup>3</sup> To further ensure the representativeness of this sample, we shared the proportions of people with different impairments using the Government's Family Resources Survey. We asked Savanta to match our sample to this as closely as possible.

A second difficulty is that reaching a representative sample of the disabled population with an online survey is more challenging than it would be for a whole population sample. The proportion of people who will not be reached by or able to respond to an online survey is likely to be higher in the disabled population than the population as a whole.

We investigated the possibility of commissioning some telephone surveys as part of this work. However, this has its own drawbacks. Firstly, it greatly increases the cost of the work, and to fit it within our budget, we would have had to substantially decrease either the number of questions we asked or the size of our sample. Secondly, even telephone surveys would not necessarily be suitable for some disabled people. Given this, we decided it was best to do an online survey as planned, acknowledge these issues and caveat findings accordingly.

## Calculating social care eligibility

From our sample, we wanted to estimate the number of working-age disabled adults who may be eligible for social care but do not receive it. To do this, our survey had questions reflecting the criteria for social care eligibility laid out in the Care Act.

The Care Act specifies ten outcomes and says that a person may be eligible for social care if their impairment or illness has a significant impact on their wellbeing and if they are unable to achieve two or more of the specified

---

<sup>3</sup> ['Leonard Cheshire – Disabled Adults Polling', Savanta, April 2022](#)

outcomes. It defines being unable to achieve the outcomes as also encompassing:

- Being able to achieve them but doing so causes the person significant pain, distress or anxiety.
- Being able to achieve them but doing so endangering the health or safety of the person or others.
- Being able to achieve them, but it is taking significantly longer than would usually be expected.

To reflect the Care Act, we asked our respondents about their ability to achieve each of these ten outcomes without causing themselves pain, distress, or anxiety, without endangering the health and safety of themselves or others, and without it taking longer than expected.

*When your disability or condition affects you, which of the following activities are you able to do independently, able to do with difficulty, or unable to do at all without help?*

	I can do this independently.	I can do this safely, but it causes myself or others pain, distress or anxiety.	I can do this safely, but it takes me a lot longer than I'd like	I can do this, but it puts myself or others in danger	I can't do this at all without help
Preparing meals and eating and drinking					
Keeping yourself and your clothes clean					
Using the toilet					
Choosing clothes and getting dressed.					
Keeping yourself and others safe in your home					

Cleaning and tidying your home					
Building and keeping relationships with family and friends					
Getting a job, accessing education or doing volunteer work					
Using public transport and local facilities					
Caring for any children you have					

To mirror the Care Act, we also asked if their impairment or illness impacts their wellbeing.

*Does being unable to do those activities independently impact your mental or physical wellbeing?*

Yes

No

Don't know

Prefer not to say

By asking these two questions, we ensured that we matched the criteria for social care eligibility under the Care Act as closely as possible. Mirroring the Care Act, we therefore created our calculation of how many people are potentially eligible for social care based on respondents who:

- Responded, 'I can do this safely, but it causes myself or others pain, distress or anxiety' or 'I can do this safely, but it takes me a lot longer than I'd like' or 'I can do this, but it puts myself or others in danger' or 'I can't do this at all without help' to two or more of the ten outcomes;

AND

- Ticked 'Yes' to being unable to achieve those outcomes independently, having an impact on their mental or physical wellbeing.

The respondents who fit this criteria is our figure for how many people may be eligible for social care.

## **Caveats with our eligibility calculation**

While we have matched the Care Act as far as possible, an online survey is different from a formal care assessment. Therefore, all our figures in this report on how many people may be eligible for social care should be seen as estimates.

When we say that people may be eligible for social care, we are not saying that a care assessment would find them eligible; we are saying that their self-reported description of their illness or impairment suggests that they *may* meet the criteria for local authority-funded social care.

Our questions also only focus on respondents' illnesses and impairments and whether they are likely to meet the threshold to receive social care. We have not looked at financial eligibility, another element of the social care assessment process. Someone can be assessed as eligible for social care based on their illness or impairment but adjudged as not eligible due to their financial situation. Therefore, there are people in our sample who may meet the criteria for social care in terms of their needs but would not ultimately receive local authority-funded social care because of their financial situation.

## **Calculating unmet need**

The final figure we needed to generate was for unmet need. This is the number of people who may be eligible for social care but who are not receiving it.

The methodology described above generated the figure we needed for the first part, which is the number of people who may be eligible for social care. To calculate unmet need, we needed to establish how many of those people have never accessed social care.

We decided to only look at those who have never accessed social care, therefore excluding those who have accessed social care in the past but no longer do so. We did this because to know whether somebody who previously received social care but no longer does should be considered as having unmet need we would need to have a detailed understanding of why their social care ceased. Given the constraints of our research, we could not get enough detail on each respondent who has stopped receiving social care to be able to judge whether they should be considered to have unmet need. Therefore, we decided to exclude respondents who used to receive social care in our calculations to avoid the risk of erroneously inflating our figure.

Calculating unmet needs requires combining answers from two more questions.

*Do you currently receive any social care support?*

Yes - I currently access support (e.g. either organised by my local council or that I pay for privately)

No, but I am currently waiting for a care assessment or for care and support to begin

No, but I used to access social care

No, I have never accessed social care

Don't know.

Prefer not to say.

Those who answered that they had never accessed social care were shown the following question.

*Why have you never received social care support?*

I receive help from a friend or family member

I don't think I can get any support for my needs

I don't want or need any further help

I use state benefits, like Personal Independence Payment (PIP) to meet my needs instead

I don't know where to go to get support

I can't afford to pay for care or council care contributions

I asked the council or the NHS about getting support, but it was too difficult to get the help I need

My local council told me I was not eligible for care

My local social care services have closed

Other

Don't know

We used the first question to filter down only to those who say they have never accessed social care. We used the second question to filter out those who receive help from a friend or family member, don't want or need help, use state benefits to meet their needs, or have been told they are not eligible. This is not to say that people in those categories do not have needs that could be better met. But we wanted to focus purely on those who have never been through the system and are not receiving any help, not by choice.

Combining these questions with our previous calculations on social care eligibility, we generated our figure for unmet need. This calculation is based on respondents who:

- Meet our previously stated criteria for unmet need.

AND

- Answered 'No, I have never accessed social care' to whether they are currently accessing social care.

AND

- Answered 'I don't think I can get any support for my needs' or 'I don't know where to go to get support' or 'I can't afford to pay for care or council care contributions' or 'I asked the Council or the NHS about getting support, but it was too difficult to get the help I need' or 'My local social care services have closed'.

From our sample of 1,504 people, 425 met this criteria. This gives us our figure of 28% of the population of disabled working-age adults who may be eligible for social care but have never received it.



**healthwatch**

Healthwatch England  
National Customer Service Centre  
Citygate  
Gallowgate  
Newcastle upon Tyne  
NE1 4PA

[www.healthwatch.co.uk](http://www.healthwatch.co.uk)

t: 03000 683 000

e: [enquiries@healthwatch.co.uk](mailto:enquiries@healthwatch.co.uk)

 [@HealthwatchE](https://twitter.com/HealthwatchE)

 [Facebook.com/HealthwatchE](https://www.facebook.com/HealthwatchE)