

Research report

Experiences of challenging adult social care decisions: In- depth interviews

February 2023

Research in Practice

© 2023 Equality and Human Rights Commission

First published February 2023

ISBN: 978-1-84206-860-1

Research report number 143

Equality and Human Rights Commission Research Report Series

The Equality and Human Rights Commission Research Report Series publishes research carried out for us by commissioned researchers.

The views expressed in this report are those of the authors and do not necessarily represent the views of the Equality and Human Rights Commission. We are publishing the report as a contribution to discussion and debate.

Please contact the Research Team for information about our other research reports, or [visit our website](#).

Post: Research Team
 Equality and Human Rights Commission
 Arndale House
 The Arndale Centre
 Manchester M4 3AQ

Email: research@equalityhumanrights.com

For information on accessing one of our publications in an alternative format, please contact: correspondence@equalityhumanrights.com.

Contents

Acknowledgements	50
Executive summary	4
1. Introduction	7
1.1 Aims of the research	7
1.2 Context of the research.....	8
1.3 Methodology	12
2. What people said about adult social care decisions	17
2.1 About the decisions.....	18
2.2 Why people were unhappy with decisions	19
2.3 The impact of decisions	21
2.4 Issues that were related to people’s characteristics	23
3. What people said about challenging adult social care decisions	25
3.1 About the challenges.....	25
3.2 The outcome of challenges	27
3.3 Not challenging	29
3.4 The impact of challenging decisions	30
3.5 Issues that were related to people’s characteristics	32
4. What helped or did not help people to challenge adult social care decisions	34
4.1 Enablers to challenging adult social care decisions	34
4.2 Barriers to challenging adult social care decisions.....	36
4.3 Different routes for challenging adult social care decisions.....	38
4.4 The role of advocacy in challenging adult social care decisions	41

5. What people think would help to improve experiences of challenging decisions about adult social care	43
5.1 Suggestions to help people who use the adult social care system	43
5.2 Suggestions for local authorities	44
5.3 Suggestions that were related to people’s characteristics.....	46
6. Summary and conclusions.....	48
References.....	50
Appendix.....	53
Questions that we asked.....	53
Contacts.....	55
EASS	55



Executive summary

This report provides information about people's experiences of challenging, or attempting to challenge, decisions about their adult social care or support. The research was commissioned to inform the Equality and Human Rights Commission (EHRC) statutory inquiry into challenging decisions about adult social care in England and Wales, which looked at:

- decisions in relation to assessment of care or support needs
- decisions about how or where social care or support needs will be met, and
- decisions that result in a change in the needs that the local authority accepts require care or support, or a change of care or support package upon review.

This could include decisions about financial assessment and charging when this was related to the three areas above.

Legal rules around assessment, care and support and review are intended to ensure equitable access to social care rights, but our findings suggest that poor decisions by local authorities and barriers to challenging decisions mean that people's needs are not always being met and their rights not always upheld.

All adults and carers have rights under the law, but existing research about adult social care highlights that these rights are not always upheld. Our research sought to build on that evidence by investigating people's experiences of adult social care decisions and challenges to decisions. We gathered views of adults and carers about what would improve matters for themselves and others.

We heard about experiences that had an adverse effect on people's rights, well-being and dignity. Experiences of challenge varied because of individual situations and the local authority response. Participants told us that they need information and support and that local authorities need to develop capabilities, positive behaviours and accountability mechanisms and to be given sufficient resources to fulfil their social care duties.

The issues that participants raised about decisions on assessment, care and support and review pointed to adults and carers not having sufficient information about their legal entitlements to adult social care, issues about how local authorities applied the legal criteria and lack of proactive practice by local authorities to ensure that people received their legal entitlements. This was sometimes compounded by the coronavirus (COVID-19) pandemic having made local authorities less accessible and responsive.

Some participants did not think there was any point in challenging a decision or did not have the energy to do so. Some felt discouraged by or were concerned about the potential for an adverse consequence in terms of how the local authority responded to them in future. Those who did challenge did not always follow the same path. Individual knowledge and skills, motivation and personal and financial resources all affected their ability to challenge.

Participants spoke about a number of factors that they felt made challenging more difficult. These included a lack of clarity about the process itself, ineffective processes, lack of transparency and accountability for decision-making and unhelpful behaviours from local authority staff, such as not listening or not providing information. Some participants spoke about behaviours that they perceived as unethical or dishonest.

When individual members of staff were responsive and acted on complaints, this was helpful. In some situations, participants said that challenges had led to improvement. However, many situations had not yet been resolved – and even when there was improvement, participants often spoke about adverse effects.

Most people spoke about negative experiences related to accessing or using advocacy, though there were some positive examples. Participants highlighted problems related to limited access, for example because of means testing or no advocates being available locally, and a perceived lack of independence. Advocates did not always provide the support that participants wanted (with paperwork, for example). Not all participants understood what advocacy was.

Participants said that often their experiences of challenging decisions about adult social care resulted in their needs still not being met or an ongoing adverse effect on their well-being related to health, dignity, relationships and employment. They also highlighted a loss of trust in the local authority and this had a negative impact on their confidence that they would be able to access their rights in the future.

Many of the issues arising from challenges adversely affected disabled people and people with long-term health conditions or exacerbated long-term conditions or illnesses. Some participants said that this was made worse because their impairment or illness was not understood or taken into account in the process. Participants highlighted particular experiences and barriers to challenge arising from characteristics, including health problems, age, capacity to make a decision, finance and location. Some participants highlighted the impact on other people who might face similar situations. In particular, they raised concerns about those who faced barriers such as lack of capacity.

Assessment, care and support and review are opportunities to promote equity and dignity, but adverse effects from poor decisions or difficulties in challenging add to inequity and can have a negative impact on dignity. Participants said their needs were not always met and highlighted an adverse effect on their health, well-being and dignity. They wanted to tell their story to help improve the system for others. Participants said that people need to be given clear information about their entitlements and processes and to have effective support to navigate the system. They want local authorities to ensure that staff are professional, capable, knowledgeable (about legal rules and about needs arising from health conditions and disabilities), respectful and supportive and accountable for their decisions. They also want local authorities to have sufficient resources to uphold rights.

This report is based on semi-structured interviews with 41 people that used open questions to identify participants' stories. We drew out themes relating to decision-making, challenge and outcomes. These qualitative interviews provide rich data about individual experiences that may not be representative of everyone's experience.

1. Introduction

1.1 Aims of the research

This research is part of the Equality and Human Rights Commission inquiry into challenging decisions about adult social care in England and Wales. It reports on in-depth interviews with people in England and Wales about their experiences of challenging decisions.

The primary research question for this research was: What are people's experiences of challenging, or attempting to challenge, decisions about their adult social care or support, including support for adult carers?

These qualitative interviews aimed to add to the inquiry by exploring some people's experiences in depth. Their experiences related to:

- decisions in relation to assessment of care or support needs, including which needs, if any, are accepted as requiring local authority-resourced care or support and whether and how needs are assessed
- decisions about how or where social care or support needs will be met, including the type and adequacy of care or support offered and decisions about direct payments, and
- decisions that result in a change in the needs that the local authority accepts require care or support or a change of care or support package on review.

Experiences, therefore, encompassed the initial social care decision, the person's considerations around challenging or not challenging, the challenge itself and its outcomes and the impact of these. They could include decisions about financial assessment and charging when this was related to the three areas listed above. The interviews provided the views of adults, carers and representatives (such as friends or family members) on what had happened and also their views about what would improve things for themselves and others.

The research allowed consideration of how these experiences correspond to what should happen as set out in the law.

1.2 Context of the research

Adult social care decisions made by local authorities can affect many people's access to adult social care, including whether a person is entitled to any state-funded social care, how much care or support they are entitled to and what type of care or support they can access. Rights and duties relating to adult social care decisions are set out in Box 1.

Whether someone can access appropriate care and support can have a profound influence on their equal participation in society and human rights, including their right to respect for private and family life (Article 8, Human Rights Act 1998) and their right to live independently and be included in the community (Article 19, United Nations Convention on the Rights of Persons with Disabilities).

Box 1: Relevant rights and duties

Rights to a care needs assessment, provision of care and support, and review of the care and support provided, are set out in the Care Act 2014 in England and the Social Services and Well-being (Wales) Act 2014 in Wales, regulations made under those Acts, statutory guidance in England and Codes of Practice in Wales.

There are overarching duties for local authorities to: promote well-being; provide information and advice services (including assistance in accessing care and support in Wales); to provide services or facilities or take other steps it thinks will help prevent, delay the development of, and reduce needs for care and support.. There are specific duties, relevant to the areas of this inquiry, to:

- assess the needs of adults and their carers who may be in need of care and or support, regardless of the level of their needs or their level of resources
- involve the adult and the carer, and anyone else the adult wants to be involved, in decisions relating to the adult, and involve the carer in decisions relating to them
- provide a record of the needs, assessment, and an eligibility termination, financial assessment, and copy of the care and support plan
- meet needs identified as eligible for support, and provide a care and support plan
- provide a personal budget to the individual (England only) and offer direct payments (England and Wales)
- keep the care and support package under review generally, and review it on reasonable request, and undertake a further assessment when a local authority is satisfied that circumstances have changed in a way that affects a care and support plan or a support plan, and

- provide an advocate for people who meet specified criteria and where there is no other person who could represent them.

Principles underpinning these acts include: the well-being principle, working in a person-centred way, recognising that the person is an expert in their own life, supporting people to live as independently as possible for as long as possible, reflecting the key components of the right to independent living in Article 19 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

In Wales, having due regard to the United Nations Principles for Older Persons and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

These adult social care rights are underpinned by the Equality Act 2010. This protects people from discrimination on the basis of protected characteristics. Local authorities must have 'due regard' to the need to eliminate discrimination and to advance equality of opportunity and foster good relations between those who share a particular protected characteristics and those who do not. This is called the Public Sector Equality Duty (PSED).

Adult social care law is also underpinned by the Human Rights Act 1998, which, provides that local authorities must not act in a way that is incompatible with the human rights set out in the European Convention on Human Rights (ECHR), this includes taking positive steps to protect people and that people should have a remedy if local authorities do not comply. Human rights include the right to be free from discrimination in the application of human rights (Article 14).

The rights and duties outlined here are referred to as 'legal rules' in other parts of this report.

Given the profound influence social care decisions can have on individuals' lives, it is vital that people are able to challenge adult social care decisions if they believe a decision is wrong or there is a mistake in how it was reached. In this context, it is valuable to enquire into people's experiences of adult social care decisions and challenges to decisions. This can enable deeper understanding of how far rights are upheld and what may need to change to ensure that this happens.

1.2.1 Wider social care context in England and Wales

Recent research on attitudes to social care across England, Wales and also Scotland found that 50% of those replying to the British Social Attitudes survey were very or quite dissatisfied with social care. The survey found that 59% felt that people do not get all the social care they need (Wellings et al., 2022).

Research on implementing the Care Act 2014 found that implementation was affected by the resources available, the complexity of the system and the need for culture change in local authorities (Manthorpe, 2021). Previous research has shown that some people receive fragmented and inadequate assessments, face unmet needs, experience service-led responses or are not involved in the decision-making as the law intended (Braye and Preston-Shoot, 2016). An evaluation of carers' assessments highlighted that the number undertaken continued to fall after the Care Act was implemented. It also found evidence of infrequent assessments and reviews and of shortfalls in the availability of replacement care, which negatively affected carers' well-being and employment outcomes (Fernandez et al., 2020).

Think Local Act Personal (2017) talked to adults and carers about their experiences of the Care Act 2014 assessments and associated activities. The findings further show that progress is still needed:

- 10% wanted to see more easily accessible and good quality information and advice.
- 21% wanted better quality, more flexibility or less complexity in arranging support.
- The majority of respondents (70%) said the council sometimes, rarely or never listened to them.
- More than half (54%) were involved as much as they wanted in arranging their care or support.
- Just over two-thirds (68%) were not offered the support of an advocate.

People identified issues with: lack of assessment or follow-up with support after assessment; obstacles to getting support; high thresholds to qualify for support; frustration that carers' entitlements through assessment are either not clearly understood or advertised by councils; and having to tell the same story to different professionals numerous times.

Research on the implementation of the Social Services and Well-being (Wales) Act 2014 (Llewellyn et al., 2021) found that this was a journey towards implementation rather than a completed process. Work was still needed to embed and implement the principles of the Act; for example giving carers the support they needed to engage in co-production, enabling people to have a voice in how to meet well-being needs and ensuring advocacy was accessible. Service users and carers highlighted that the social care system was facing pressures that had been exacerbated by the COVID-19 pandemic (Llewellyn et al., 2022). This resulted in them experiencing barriers to accessing services, financial considerations rationing service delivery and an impact on relational practice because of workforce churn. This research also found that some adults and carers were not aware of what the Act had to offer or experienced a ‘tick box’ culture. The researchers noted that contrasting views between adults or carers and staff in local authorities about principles and entitlements had a negative effect on well-being. However, feeling recognised, flexibility and responsiveness were elements of positive encounters. This research pointed to the need for local authority staff to have training about the Act, public communication, accessible information, specialist support for people from minoritised groups and attention to systemic issues around resources.

There are many disparities in access to adult social care related to information, knowledge, technology, systems, language, culture, suitability and prejudice and discrimination. People from particular groups can face significant barriers, for example people who are homeless or adults with autism (Nosowska, 2020).

1.3 Methodology

1.3.1 Research method

We carried out 41 semi-structured interviews, which used open questions to identify participants’ stories and then focused in on points of decision-making, challenge and outcomes (see Appendix). Interviews lasted approximately 60 minutes and were carried out online.

The interviews were transcribed and relevant points about decisions, challenges and outcomes were put into a charting spreadsheet. We pulled out and grouped themes and included all those that were relevant to the inquiry. The themes were then written up into findings, along with quotations to illustrate the points that were made.

We created an expert advisory group to review questions, methodology and analysis and to provide insight into the emerging and final messages. The group included members of a national user-led group who were able to link to a network of people with lived experience. The advisory group also included social work practitioners with legal knowledge from England and Wales. The group met five times during the project.

1.3.2 Who took part

This report is based on 41 interviews. People were contacted through three different routes:

1. We asked participants in the EHRC inquiry online survey of individuals seeking or receiving social care and / or support, who were happy to be contacted, to take part.
2. Members of the expert advisory group who were from the national user-led group advertised among this group's wider membership and contacted local advisory groups for participants.
3. We placed adverts on the WalesOnline news site and social media groups in Wales were used to promote the opportunity.

The principal roles of participants as described in their interviews are set out in Table 1. All carers primarily talked about the difficulties they experienced relating to rights for the person that they cared for; however, some carers also talked about their own experiences.

Table 1: Roles of participants

Role	Response total
Someone receiving or asking for social care	12
An unpaid carer	26

Role	Response total
Answering on behalf of someone receiving or asking for social care (such as friends or family members)	3
Total	41

We set out a quota to try to get an equal balance of participants across nations and to include participants who are known to face barriers to accessing adult social care (Nosowska, 2020). These included those with complex needs, who face language barriers or have low incomes. We proactively targeted community and user-led groups in Wales but were not able to reach our targets on these quotas.

- Of the 36 people who provided information about their age, most (n=18) were aged 40–59, though ages ranged from 18–29 to 80–89.
- Of the 37 people who provided information about their sex, 25 were female, 11 male and one non-binary.
- Of the 33 people who answered, 19 reported that their daily activities were limited because of a health condition or disability that had lasted or was expected to last at least 12 months.
- Of the 31 people who answered, 20 identified that they had a household income of less than £20,000 per year.
- One participant, out of 34 who answered, stated that English was not their first language.
- Four participants, out of 33 who answered, identified as gay, lesbian, bisexual or asexual.
- Three participants, out of 32 who answered, did not describe their ethnicity as white.

A total of 10 people spoke about experiences related to adult social care in Wales. Eight of the interviews with participants whose experiences took place in Wales were with carers of people who needed care and support and two were with adults who received care and support. Participants spoke about experiences that related to all areas of the inquiry. One of the participants from Wales was a carer for someone who had Welsh as their first language, one was a carer for someone from an ethnic minority group and two highlighted the impact of living in a rural area.

The interviews explored decisions that were taken from 2018 to 2022. Some participants spoke about more than one challenge and many participants spoke about experiences in more than one year because things had taken place over some time. Talking about the years in which challenges began, 10 participants said 2018, eight said 2019, 13 said 2020, 12 said 2021 and four said 2022. As discussed in section 3.2 of this report, many participants did not consider that the situation was resolved yet. Of those who answered the question about which local authority service area they had been involved with, 12 participants said physical disability services, 12 said learning disability services, nine said older people's services, and six said mental health services. In Wales, the services that were involved included transition for someone from children's to adult services, adult services and older people's services.

1.3.3 Limitations of the research

Although we made efforts to secure a diverse sample, there were small numbers of people from groups with certain protected characteristics and only 10 people who spoke about experiences in Wales. It may be that the barriers that affect how people access their social care entitlements (Nosowska, 2020) also prevented some groups from coming forward to take part in this research. We asked participants open questions to find out how aspects of their identity may have affected their experiences. This gave valuable insight; however, it did not comprehensively cover all the aspects of identity that might influence experiences.

The findings relate to participants' views of their experiences and are not independently corroborated. Qualitative interviews provide data about individual experiences that may not be representative of everyone's experience. Some participants had professional expertise in adult social care and others had developed a significant level of knowledge through their personal experience of this system. However, this is likely to be unrepresentative of the level of knowledge or capability to challenge that many other people in the adult social care system would have.

A small number of participants talked about experiences that were outside the scope of the inquiry and related to the Court of Protection and best interest decisions. We did not include these experiences. However, decisions and challenges relating to other areas that these participants spoke about that were in scope were included.

We attempted to include all key themes; however, in organising individual experiences into thematic groups we may have diluted or missed individual points. When conveying someone else's experience, there is inevitably some interpretation.

Participants told us about particular elements of their experience that they considered important. There may be other elements that they did not mention. Participants did not always know exact terminology, processes or roles.

Many of the experiences described took place during the COVID-19 pandemic. Some participants talked about the direct impact of the pandemic on their experience of adult social care. For others, the pandemic was part of the context that influenced their experiences. The pandemic did affect experiences, and we have tried to convey when this was an influential factor and when it was a backdrop.

2. What people said about adult social care decisions

This chapter reports on what participants told us about the decisions that had been made about their adult social care.

The inquiry was looking at:

- decisions in relation to assessment of care or support needs, including which needs, if any, are accepted as requiring local authority-resourced care or support and whether and how needs are assessed
- decisions about how or where social care or support needs will be met, including the type and adequacy of care or support offered and decisions about direct payments, and
- decisions that result in a change in the needs that the local authority accepts require care or support, or a change of care or support package upon review.

This could include decisions about financial assessment and charging when this was related to the areas listed above.

These are referred to in our report as decisions about:

- assessment
- care and support
- review, which includes a further assessment where a local authority is satisfied that circumstances have changed in a way that affects a care and support plan or a support plan.

This chapter first of all describes the decisions. Although 10 participants were talking about decisions in Wales, there were no major differences between the issues raised in the two nations. Where there is a specific point relating to Wales, this is highlighted. We highlight what participants were unhappy with and group these into themes. We then look at the impact of decisions on participants in relation to their rights. We also highlight issues that relate to protected characteristics under the Equality Act 2010 and to other characteristics. Participants in England and Wales reported similar experiences.

2.1 About the decisions

Some participants spoke about more than one decision relating to assessment, care and support or review. Although assessment, care and support and review are separated out in law and policy, the decisions that people spoke about often included consideration of more than one area (see Table 2). Most participants spoke about decisions related to adults who may draw on care and support, rather than about carers (see Table 3). However, many participants were carers and, for some of these, their story included how the decision affected them.

Table 2: Area of adult social care decision

Type of decision	Response total
Assessment only	5
Review only	6
Care and support only	15
Assessment, and care and support	4
Review, and care and support	8
All areas	3
Total	41

Table 3: Who the challenge(s) was / were about

	Response total
Adult who may have needs for care and support	29
Carer of an adult who may have needs for care and support	3
Both	9
Total	41

Participants mentioned a large number of roles of people working in social care who were involved in the decisions and they used a variety of terms to describe the local authority. Participants also spoke about specific roles, including social worker and director. Some participants talked about it being unclear who made the decision that they were unhappy with.

‘This mysterious panel ... we don't know this mysterious body and we don't know what they're refusing us on, or passing people on.’ (EH28, Representative of someone receiving care and support)

2.2 Why people were unhappy with decisions

Participants reported that they were unhappy with a range of decisions relating to assessment, care and support, and review. The reasons for this discontent with decisions were diverse.

For assessments, issues that participants raised were:

- Assessments for care and support or for carer's support were not carried out.
- Assessments were narrow and did not consider all the person's needs or prevention of needs, so did not lead to full consideration of how to meet needs; this was sometimes because assessors did not always understand the person's health condition.

‘ ... within five, ten minutes, she again stated that she could tell immediately from the get-go through my health conditions it would be pointless continuing with the full adult needs assessment under the Care Act because it was pretty obvious that I wouldn’t meet the criteria.’ (EH09, Adult receiving assessment)

For care and support, participants raised the following issues:

- One person was told that care was not available.
- The local authority set limits on how much resource could be provided, for example for short breaks for carers, and this was not considered sufficient or sufficiently flexible.
- There was no follow-up to check on care and support provision.
- There was limited choice about how needs could be met. For example, 24-hour care could only be provided in a care home or visits did not correspond to someone’s routine.

‘They said that social services said to the college that they could put another student to bed at eight o'clock and then S could have the extra care, but these are students who are 18, 19 and 20, they can't go to bed at eight o'clock.’ (EH30, Carer, Wales)

There were also issues with charges for care and support being increased without consultation and lack of information about how disability-related expenditure should be taken into account in charging decisions.

For review, issues that participants raised were:

- Reviews were done when the participant thought they were unnecessary as their needs were not going to change, or reviews were not done although they were asked for.
- Local authority staff did not prepare before the review or do a comprehensive review.
- Carers were not listened to.

Many participants said that decisions were made to cut or reduce care and support when there was either no change in needs or no reassessment done. This included reducing the amount of direct payments. This was related to issues that participants raised about local authority staff not understanding the participants’ particular needs, for example if they had autism or mental health conditions.

‘It was basically that the council cut my support by three-quarters when there was basically absolutely no change at all in my condition.’ (EH01, Adult receiving care and support)

For all decision areas, there were recurring issues relating to: the length of time taken to respond and make decisions, which some participants saw as a form of rationing; lack of involvement in decisions; lack of information (for example, not providing a copy of the assessment or care plan); and inaccurate information in written documents.

One participant talked about difficulties in accessing their entitlement to carer's respite because of a lack of availability of respite.

'... if a carer is told, "you've got 42 days respite from care in a year", that should be legally guaranteed. So, if they want to take respite from care, they can, and any care covering is paid for by stakeholders, not the carer.' (EH40, Carer, Wales)

The same participant said that they had to pay for cover when they had respite.

'What I was not told until I'd almost arranged everything was, "by the way, you have to provide cover". So, I said, "okay, I have no objections to that. How is cover provided?" "We just bring in the people who would be there when you're not there. It'll be £4,000 for the two weeks." My jaw just dropped. The Welsh Health and Social Care Act provision said I'll get respite from care. Respite from care for me should not mean I get lumbered with a £4,000 bill. Unfortunately, those are the rules, so I just had to agree to them.' (EH40, Carer, Wales)

Another participant, who was a carer based in England of someone receiving services in Wales, highlighted communication difficulties between the decision-making local authority and the provider.

Some participants' concerns were about services closing during the COVID-19 pandemic without alternative provision or information. These included day centre provision and short-break services in residential homes. Some participants also talked about decisions during the pandemic being made on the basis of limited information due to people not being seen face to face.

2.3 The impact of decisions

Participants told us that the decisions with regard to assessment, care and support and review affected their rights and dignity in a number of ways.

Needs not met

Participants said that some decisions led to people not having what they needed. This could be because they felt a service that they had been provided with did not meet their needs or was not appropriate (for example, a placement in a care home rather than being at home) or they felt that there was risk that was not being managed (for example, someone not having support to eat well).

Impact on well-being

Participants experienced an impact on well-being. Participants told us about adverse effects on their physical and mental health, particularly from stress and anxiety. Some participants' relationships within the family were negatively affected by the strain. A few participants highlighted that care and support, which they considered insufficient or inappropriate, affected their ability to work or study, or to parent.

'It's affected my health so badly that I am now on beta-blockers for anxiety, which I've never been on in my life. I was in hospital seriously ill earlier in the year, brought on by gastric issues ... which were triggered by nerves and stress. I'm still on the beta-blockers. That's a permanent thing now. The stress has been absolutely overwhelming.' (EH14, Carer)

Some people said that they felt degraded or worthless because of decisions that made them feel like they were not respected, either because they were not listened to or did not receive the support they felt they needed.

'There is also an element of – how can I put this – degradation I suppose ... So my self-image has suffered ... To suddenly have a living environment where you have dust all over the floor or your coffee table has about five months' worth of stains and is actually very unhygienic ... To live like that you don't feel clean. You don't feel like a respectable human being I suppose. So I guess you could say it's taken away my self-respect in certain ways.' (EH09, Adult receiving an assessment)

There was also a financial impact for some participants who decided to pay for services that were not provided by the local authority.

'We're not a wealthy family, but we pay out a huge amount of money to give extra support to [our adult son].' (EH10, Carer)

Concern about future entitlements

Participants felt they had less chance of exercising their rights in the future. This was because they had lost trust in the local authority to fulfil its duties.

‘It made him and me as well go, “Is this all just stupid? Shall we just give up?” He was saying, “Is it better I just don't get any kind of support from the council, because it's not worth the distress?”’ (EH32, Carer)

2.4 Issues that were related to people's characteristics

Many of the issues arising from decisions about assessment, care and support and review adversely affected disabled people and people with long-term health conditions. Participants said that the decisions they were unhappy with exacerbated long-term conditions or illnesses and that particular long-term conditions or illnesses were not fully taken into account in decision-making. These included learning disabilities, autism, Down's syndrome and ME / CFS (myalgic encephalomyelitis or chronic fatigue syndrome).

‘The woman's [practitioner's] attitude to autism anyway was completely Victorian. She didn't know anything about autism, she didn't understand about hyper sensory experience or echolalia. They don't understand these terms.’ (EH27, Carer)

A few participants said that their age affected the quality of the decision because policies were geared to either older adults or children, so working-age adults did not have the support they needed.

Other aspects relating to identity that were raised were:

- not having a choice about the sex or age of staff to work with someone, which affected that person's sense of control and trust or meant that the support did not feel appropriate

‘I particularly asked for a male carer, you see. I wasn't expecting a woman, but I didn't get one, and they said that there wasn't male carers available ... A lass of 27 trying to make conversation with a man of 90. There's just nothing there at all.’ (EH41, Carer, Wales)

- lack of care and support offered to people who wanted to work or needed support to parent
- lack of support to carers who were working or studying

- the local authority not contacting someone in their preferred language or taking their cultural needs into account (this was in Wales but did not relate to Welsh language).

‘I’m a newcomer, I see myself as an outsider, bringing something, more layer of diversity, and the language is an issue when you don’t understand the system. That would be very helpful to have some of the information in other languages spoken, international languages. That would be very helpful.’ (EH03, Carer, Wales)

3. What people said about challenging adult social care decisions

This chapter reports on what participants told us about the experience of challenging adult social care decisions about assessment, care and support and review. Participants in England and Wales reported similar experiences. Specific points relating to Wales are highlighted.

The chapter looks at the challenges broken down by the reasons, the route that participants took, who was involved and the outcome of challenges. For those who did not challenge, we explore what they told us about their decision not to challenge. We set out what participants told us about the impact of the experience and the outcomes of challenges. We highlight issues that relate to protected characteristics under the Equality Act 2010 and to other characteristics.

3.1 About the challenges

The reasons for challenging arose from the issues with decisions that participants had identified, as set out in the previous chapter.

Participants told us about a number of different routes they had taken to challenge decisions about assessment, care and support and review. Often participants took more than one route, and they were not always clear about the sequence of events.

Some participants said they sought to challenge the decision by talking to or writing a letter to someone in the local authority but did not discuss this in terms of using the complaints process. These participants had help from different sources, such as a solicitor, a social worker, a councillor, a voluntary organisation or a friend.

About half of participants had followed the local authority's complaints process. The complaints process was usually an internal process, though in at least one case in England we were told that it was outsourced and was provided by the local PALS (Patient Advice and Liaison Service).

The majority of participants who put in a formal complaint had done more than just raise the complaint:

- Some had involved other people, including a director of adult social care, councillor, MP, solicitor or relative.
- A few had complained and then further challenged the complaint decision through a second stage of the complaints process.
- Some had contacted the relevant ombudsman after complaining to the local authority.
- In one situation, a judicial review had occurred.

From participants in Wales, we heard examples of a member of the Senedd (or Welsh Parliament) asking for an independent social worker to review the situation. This seemed to have followed from the participants writing to their Senedd representative.

Participants mentioned a number of roles of people who were involved in challenges and the frequency of mentions indicates which roles were most relevant to challenges for these participants (see Table 4).

Table 4: Roles mentioned in relation to challenge

Roles mentioned in relation to the challenge	Total of direct mentions in interviews
Local authority / council / social services	140
Advocate	48
Lawyer / solicitor	44
Carer	38
Ombudsman	23
Friend	19
Family	18
Councillor / MP / Member of the Senedd	15
Judge	12
Agency	11
Doctor	10
Director of adult social care	7
Total	385

3.2 The outcome of challenges

Participants told us about the outcomes of their challenges to decisions relating to assessment, care and support and review. Outcomes of challenges were not clear-cut.

In some situations, participants had decided not to pursue a challenge (see 3.3).

Approximately a third of participants told us that challenges resulted in positive actions that improved care and support.

‘Now, she’s finally gone to a home where she’s happy and she’s settled, and the parents love the new home and their visits have gone up every week and they’re looking to bring her back to X, hopefully, which is lovely, because that’s where all her friends are.’ (EH28, Representative of someone receiving care and support)

‘He got more hours, so his hours increased from four to I'm not sure if it's 12 or 15.’ (EH32, Carer)

In some situations, there were positive responses acknowledging that a mistake had been made or apologising. Some participants who challenged said this resulted in greater learning or confidence for them.

In approximately a third of situations, the situation was not yet resolved.

‘I have no expectation. This is it. We're going to be where we need to be. In fact my expectation is that I'm going to have to jump through the hoops and go back to the ombudsman and then start it all over again. I'm just going to have to keep doing that until one of us dies.’ (EH04, Carer)

Even when the challenge had led to improvement, the experience was still seen as negative in some respects. Some felt frustrated that they had to go through a process of challenge to get what should have been there in the first place or to reinstate what should never have been removed. For some participants there was a financial impact due to the process or because they had to pay for care while things were resolved. Some participants said they had not received an apology, acknowledgement or full information and others were concerned about decisions that might be taken in the future.

‘Yes, it took two, nearly three years, but they've given it back. But what's changed? Within the reason why you took it off me, you're not allowed to use it to run a business, to three years later to give it me back to help me run a business or to help me do my business, I should say, what's changed? Nothing has actually changed.’ (EH24, Adult receiving care and support)

3.3 Not challenging

Some participants said that they had decided not to challenge. The reasons for this can be grouped as follows.

Barriers related to capabilities or resources

Some participants said that their health condition or lack of energy had prevented them from pursuing a complaint.

'I couldn't be bothered. Head against the brick wall, and there's so much going on in my life that I just could not be bothered to do that.' (EH41, Carer, Wales)

Others said they had needed help or had sought help from voluntary organisations, but this was not available. A few participants mentioned that they had stopped pursuing a challenge once they had reached a point of needing to pay for a solicitor to go to court. One participant highlighted the lack of funding to challenge local authorities.

'So there's no funding going to independently challenge councils over decisions they make with the millions of pounds that they have. I find it difficult. Difficult is probably the wrong word at times. Impossible. I cannot challenge the council effectively as I would like.' (EH25, Advocate)

Barriers related to feelings of powerlessness

Some participants said they had considered making a complaint but did not feel it would be successful because a decision had already been made by the local authority and they did not think it would change if the local authority looked at it again. One person said that they were told that nothing could be done because this was how the care and support had to work; this related to having to receive direct payment money through a prepayment card.

'The social worker mentioned to me the last time I spoke to her, if I wanted to make a complaint, I was perfectly within my rights! I just said, "Well, I don't think I'll be doing that, do you?!" Because what's the point?' (EH29, Carer)

Barriers related to discouragement

Some people said that they felt discouraged from challenging. This was related to a number of different experiences: not receiving information; not being able to get hold of people in the local authority; not receiving replies to emails; and being told by a carers' lead that it was time to 'draw a line under' a situation.

'... she [Carers' Lead] said straightaway when she came, "Let's draw a line under this all now, X," and I thought, that's interesting.' (EH23, Carer)

One participant, who received care and support, said they were apprehensive about making a complaint in case of an adverse reaction in terms of how the local authority responded to them in future. They did not explain further what this reaction might be.

Some participants who were challenging decisions said that they were concerned about other people in the adult social care system who might not be able to do this because of the stress, the energy needed or the cost, or because they feel they do not have the power to change things. Participants who decided not to challenge also felt adverse impacts from the decisions and from the experience of deciding whether or not to challenge.

3.4 The impact of challenging decisions

The experience of challenging decisions relating to assessment, care and support and review affected participants' rights and dignity in ways that were similar to the impact on participants arising from the actual decisions.

Needs not met

When decisions had not changed or challenges were not yet resolved satisfactorily, participants felt that their needs were not being met; for example, they felt that they needed more care and support or a particular service that was not in place.

Impact on well-being and dignity

Participants experienced an adverse impact on well-being. They highlighted the impact on their health, including both physical and mental health.

'I left the meeting, I started to fight for my breath and what-not. I'd had chest pains the night before. I don't know whether it was the stress and I was worried about the heart.' (EH15, Carer)

A few people spoke about the impact on their dignity. For example, one participant said that the experience of challenging made their friend feel 'illegitimate', as if they were making things up or did not really have needs. Another said that they were made to feel that as if they did not exist.

'The simple answer is I have been made to feel as if I didn't exist on more than one occasion to such a degree I've actually said, to the council, "you would much rather I wasn't here, wouldn't you?" They've never answered the question.' (EH40, Carer, Wales)

There was a particular emphasis on the emotional impacts of challenging, including frustration, despondency and stress. The experience of the challenge could trigger recollections of previous difficulties and lead to despondency about adult social care.

'I won't say I'm depressed. I don't think I'm actually depressed, but I get very, very fed up with it and despondent, and lose motivation for things. So if I had sufficient help, and if I had the respite breaks without having to work so hard for the few that I get, Mum would be able to stay at home longer, I'd be happier, I'd be able to have more energy. I'd be able to do things that I enjoy doing, whereas at the moment, I can't.' (EH37, Carer, Wales)

Impact on relationships

Some participants also spoke about an adverse impact on their relationships with other people.

'Then the effect on the other family members, my daughter helps me an awful lot, and she's a very clever, professional person, but she's got two young children and she's bothered about me all the time. The stress levels of her keeping her job down, looking after me, bothered about her dad, you can see the ripples.' (EH10, Carer)

Impact on finances

For some participants, there was a financial impact from challenging. This was related to paying a solicitor for advice and help with preparing paperwork.

Concern about future entitlements

Participants felt they had less chance of exercising their rights in the future due to a loss of trust in adult social care. They told us that they were worried about the next review or decision-making point in case the process of challenge needed to start again.

‘I think I’m probably just waiting for the next battle now. You’re always ready for the next one. I’ve got no faith in social services and it’s especially upsetting when they lie as well. I think when one battle ends, there’s another just waiting.’ (EH30, Carer, Wales)

Positive impact

When the outcome of the challenge was seen as an improvement, there was some positive impact for participants.

‘I fought. I really believe in where possible, keep families together, and I’m just really pleased now that she’s happy and the mum, you can hear the relief in the mum’s voice. All she wants was the best for her daughter.’ (EH28, Representative of someone receiving care and support)

3.5 Issues that were related to people’s characteristics

Many of the issues arising from challenges with regard to assessment, care and support and review adversely affected disabled people and people with long-term health conditions.

‘It has made me ill, yes ... I mean I ended up completely just screaming and shouting for weeks on end because I was in such a state. I didn’t know what to do. I was having all these emails and being told this and having all these meetings. It was just ... I didn't know what to do.’ (EH19, Adult receiving care and support)

Participants said that the experience of challenging exacerbated long-term conditions or illnesses and that particular long-term conditions or illnesses made challenging more difficult. For example, one person said that because they were autistic their experience that the local authority had not done what they believed it should under the rules was particularly distressing.

The opportunity and ability to challenge was related to each participant’s particular situation (see next section). Participants noted that some people do not have the skills, ability, knowledge or resource to challenge.

‘I’ve had to go through and read the statutory guidance to understand that what they were doing was unlawful. Most people wouldn’t do that, would they?’ (EH01, Adult receiving care and support)

In some situations, it appeared that the experience of challenging was more difficult because of the participant’s characteristics. One participant said that they were not supported to challenge because they were seen as intelligent and capable so could do this themselves. Another said that their rural location in Wales made it more difficult for the local authority to respond, both in terms of looking into the challenge and changing the decision.

One participant had asked for a reasonable adjustment – to have a different venue for a meeting about a challenge – and felt that this request led to resentment from the local authority.

‘... and the person’s very disengaged and very resentful to be there, I think partly because it was off premises, because it was meant to be a venue that wasn’t his home, and it wasn’t the office. It felt like there was a lot of resentment there to be asked to make an adjustment and do something out of normal, but yes, we definitely complained about it.’ (EH32, Carer)

Some participants highlighted the impact on other people who might face similar situations. They stated that they were in a better position to challenge because of capabilities or resources, and raised concerns about those who faced barriers such as lack of capacity.

‘I would say that the barriers to actually successfully challenging a reduction in a care package are mountainous and multiple; that barriers are so extensive that it is analogous to saying to a disabled person, “This is what you get; if you wanted to challenge this, go climb Everest.” Seriously, it’s like trek across the desert, do impossible things before breakfast. Like I say, this is why I think the example with [my friend] is in some ways so powerful because if we can’t challenge it then how the heck is an ordinary member of the public to challenge it?! Especially those who don’t have vocal capable family members to stick up for them – and there are plenty of those; those who lack capacity to make the relevant decisions.’ (EH08, Friend of adult receiving care and support)

4. What helped or did not help people to challenge adult social care decisions

This chapter reports on what participants told us about factors that either helped or did not help them to challenge adult social care decisions. It looks at factors that affected different routes that participants took to challenge. We particularly look at advocacy as a factor in either helping or hindering challenges. We highlight issues that relate to protected characteristics under the Equality Act 2010 and to other characteristics. Participants in England and Wales reported similar factors.

4.1 Enablers to challenging adult social care decisions

Participants told us about what helped them to challenge adult social care decisions.

Participants' capabilities

Some participants had developed an understanding of, and expertise in, adult social care through their experiences or by attending courses run by the voluntary sector. Some had professional expertise or experience in government, and some participants were representatives with advocacy or other training. Participants highlighted the importance of being assertive; they stated that they had the determination to fight for the rights of a family member and the psychological reserves to keep motivated.

'Then I wrote to the ombudsman and complained, and I know about GDPR [General Data Protection Regulation], I'm a lawyer.'
(EH04, Carer)

‘As I love C so much and I know I’m fab, I’m not ready to give up, but I was absolutely going to tell them just to take him, and it’s my love for him and knowing what crap my friends have had in supported living that has stopped me. January is here, so I’m going to be Positive P.’ (EH23, Carer)

Participants’ resources and networks

Participants talked about specific help that they received from others. This help might be: from friends or family who had knowledge of adult social care and helped with complaint letters; from advocates who attended meetings; from voluntary organisations that provided information; and from elected representatives who contacted the local authority.

‘I went to the local Carers Support people ... I would say that was reasonably influential for me because all the experiences I’ve had with that organisation have been good ... I think I was able to get quality information from them, understand that there was a different route.’ (EH16, Carer)

Money was another resource that enabled participants to make a challenge – for example, to pay for a solicitor.

Local authority professionals

The factors relating to the local authority were generally negative. However, some participants did experience positive support from a person working in the local authority, including someone responding to the complaint, a practitioner, a manager, a director, a solicitor or a commissioner. Some participants said that the challenge resulted in the decision being reconsidered by a more experienced or expert practitioner, and they found this helpful.

‘It very much felt like the [social worker] that we were working with was very positive and pragmatic and, “How can we fix this?” and, “What can we do?” and, “I’ll do everything that I can to get this done so you can get back to having a bit of a life and recovering and stabilising.”’ (EH32, Carer)

One participant had support from care workers, who provided information to the local authority to evidence the person’s need for care and support.

Local authority complaints process

The complaints process was usually a negative experience (see next section), but not always. One person talked about the process working simply and as expected.

‘When I made a formal complaint, the Council obviously have a complaints process and upon making that complaint, I was told how long it would be before I would hear back. I heard back within the time frame and as it was, the complaint was upheld. The actual process of making a complaint was fairly simple and the process worked, I think, pretty much as it’s prescribed.’
(EH16, Carer)

4.2 Barriers to challenging adult social care decisions

Participants told us about the factors that hindered them from challenging adult social care decisions, including the following.

Personal circumstances

Participants told us that challenging a social care decision was made more difficult because of lack of time, stress or caring responsibilities. Participants talked about how their physical health made it more difficult to challenge, for example because they were tired or unwell.

‘Initially, I tried to challenge them and they just kept saying look, you’re getting everything you’re entitled to, there’s nothing we can do. Then I got too sick, so I had to – I was just not well enough, I was barely functioning. I’d had to stop work because I was too ill.’ (EH07, Adult receiving care and support)

Lack of resources

Participants told us that they did not have access to a lawyer or legal aid (it was not clear how this related to eligibility criteria for legal aid), there was no available voluntary sector support, there was limited or no advocacy services or they had limited response from an MP or councillor. Some people highlighted the cost of challenging, for example, related to the cost of paying a lawyer.

‘I’ve approached numerous other organisations for help with the complaint. I approached the Citizens Advice Bureau and my local Healthwatch and several other organisations and they couldn’t help me make a complaint.’ (EH09, Adult receiving care and support)

Local authority barriers

Participants told us that many of the barriers related to the local authority.

- The process for challenging was not clear to participants.
- Participants shared experiences of not being able to find or understand information about how to complain, not knowing how to challenge further if the initial challenge did not result in the outcome they wanted or not being told about the relevant ombudsman.
- The process for challenging was not effective.
- The behaviours of local authority staff were unhelpful.

Some participants were concerned that the complaints process within local authorities involved services looking at their own decisions and so would not be impartial or independent.

‘Having had that assessment, I tried to challenge it, but X social services have a wonderful complaints system, and if you complain about somebody, they give that somebody the complaint to deal with. So they investigate their own complaint.’
(EH04, Carer)

However, in one situation in England, the process was outsourced to an advice service and the participant did not think this service would have the expertise to resolve the complaint.

Participants shared experiences about a lack of response from the local authority, such as not being given evidence that was asked for or not answering questions. Other concerns were the local authority not responding within timescales and not putting things in writing, or people who worked in the local authority not understanding the law well enough to respond.

‘I sent a response ten weeks ago and I’ve asked for a response back to that and I’ve not got one. I’ve not got a response back to any of the points ... until I hear from them, I’m just carrying on doing what I’m doing because I’ve asked them, “Right, this is my response. What have you got to say back?” I’ve not had anything, and I’ve asked three times for a response back, so like I say, this is why I’ve not heard from them.’ (EH19, Adult receiving care and support)

One of the issues raised by participants was a feeling of lack of accountability from the local authority. Some participants felt that there was limited incentive for local authorities to resolve complaints. One person said:

‘They know that, essentially, if someone complains and takes it to the ombudsman, worst case scenario for the council is they’ll have to reinstate it.’ (EH01, Adult receiving care and support)

Participants described behaviours from people in the local authority that made it more difficult to challenge. These included: not listening to a person's carer; participants having to repeat their concerns because they did not get an answer when they raised an issue; and not being believed.

Some participants talked about experiencing unethical or dishonest behaviours from people in the local authority, such as: deliberately not sharing information; criticising people for challenging; and giving false information.

'Because I've had to challenge them, and rightly so, they loathe me and they will do anything they can to write things to keep excluding me really. It's just horrendous, because the lies that are written to cover their backs are shocking.' (EH11, Adult receiving care and support)

The COVID-19 pandemic had some influence on the process of challenging decisions. Participants said that it was more difficult to get hold of people in the local authority or that they would not come out to see them. Advocates could not build relationships as easily and local authorities were very busy.

4.3 Different routes for challenging adult social care decisions

Experiences in England and Wales were similar. Participants told us about a number of different routes they had taken to challenge decisions about assessment, care and support and review. The routes that were mentioned were:

- informally talking to or writing to people in the local authority about the situation
- making a complaint under the formal complaints process (this was usually an internal process in the local authority, though in one case it was outsourced)
- escalating a complaint to the next stage of the complaints process
- taking a complaint to the ombudsman if participants were dissatisfied with the complaint outcome at local authority level, and
- taking a legal case against the local authority (participants mentioned this as judicial review).

Informal routes for challenging decisions about adult social care worked for several participants. Participants who did this had some confidence and ability to raise issues, had some expertise in raising issues or had help from a friend or a solicitor who could write a letter for them.

Most participants talked about using the local authority complaints process. The experiences that participants shared of how the process worked, and whether the outcomes were positive for them, seemed to be related to the capability and resource of the person, the ease of process – in terms of finding out how to complain and making the complaint – and the responsiveness of the local authority. Some participants put in multiple complaints and saw this as part of their role as a carer in getting the best decisions for the person they cared for.

Some participants told us that a leader – such as a senior person in the local authority, a councillor or an MP, or member of the Senedd (or Welsh Parliament) – was contacted to support the complaint or escalate it if it was not being resolved in a timely way. It was not generally clear whether this made a difference. In a few cases in Wales, the involvement of a member of the Senedd did lead to an independent social worker being appointed to give an independent view. In a few situations, the involvement of the local authority leader or elected representative did result in a change to the decision; for example one local authority cabinet member got a service restarted for an adult the following day.

The complaints process was criticised in some situations for being unclear, taking too long, not being followed or being too complex. Most complaints were dealt with internally and some participants considered that the system was biased.

'Even if you feel you've got the administrative ability to take the council on and the complaints procedure ... it's designed not to answer your complaint ... That's how complaint systems are designed to just ... wear them down, and that's why a lot of people I know with mental health social needs over the years, just don't do it. They don't seek complaints.' (EH25, Advocate)

In one example, the local authority had outsourced its complaints process to PALS and the participant said that this did not work, as PALS was an advice service rather than a complaints service.

Some participants told us that they escalated their complaint if it was not resolved to their satisfaction. Again, this was linked to their capability and the support available. Some people continued the complaint with the local authority. Participants talked about a next stage that was also handled by the local authority. One participant in England who was involved in this process said that it felt futile, as the same decision was likely to be made again.

Some people complained to the ombudsman following the outcome of a complaint to their local authority. Outcomes from this process varied: there was reinstatement of care; the ombudsman endorsed the local authority's decision; or the ombudsman process had not concluded.

We were told that one local authority in Wales suggested the participant go to the ombudsman with their complaint as they had already complained about this previously. The ombudsman referred the complaint back for an internal review.

‘The complaints department wrote back to me and said that I’d already made a complaint regarding the independent assessment, and therefore if I wasn’t happy with the outcome, I should go to the Ombudsman ... We had a letter back from the Ombudsman saying they’d spoken to X Council, who has told them that it’s not been through a Stage 2 complaints procedure, so the Ombudsman rejected our complaint ... It was then they acknowledged the Stage 1 complaint.’ (EH34, Carer, Wales)

A few participants in England highlighted that the council did not inform them that they could refer their complaint to the ombudsman, and that they found information about this route themselves.

‘I found the Ombudsman by reading online. The council definitely didn’t tell me.’ (EH01, Adult receiving care and support)

An advocate talked about the importance of people with the same concern about a decision being able to challenge as a group, either through simultaneous complaints or a single collective complaint, so that a group of people could raise the same concern jointly. This was something that did not appear possible to the participant at present.

Some participants told us that judicial review was a difficult prospect. This might be because of the financial cost, the amount of information that needed to be gathered or the limited likelihood of a positive outcome. One participant told us that they had received legal aid to support them. However, other participants mentioned that cuts to legal aid made challenge more difficult. One participant said that threatening judicial review had led to a positive outcome. An advocate talked about the importance of being able to use information from judicial reviews to inform how people challenged decisions in future.

4.4 The role of advocacy in challenging adult social care decisions

Some participants talked about experiences of advocacy. Advocates provide support to people to have their voices heard in decision-making processes, including supporting people to challenge decisions about adult social care. In some situations it was clear that the person had sought the advocate themselves from the voluntary sector rather than being referred by the local authority. In other situations it was not clear how the advocate had been appointed.

Most people spoke about negative experiences related to advocacy. These can be grouped as follows.

Lack of access to advocacy

Some participants were not able to access an advocate due to a means test or because there was not an advocate in their geographical area. One participant said the local authority told them there was no advocate available and, in any case, they were capable enough not to need one.

‘They kept saying, “There isn't anybody, C,” and because I've got two law degrees and an MA and blah, blah, and I've got a brain, they think that I should be capable of doing this myself. “Why aren't you capable of doing it yourself?”’ (EH19, Adult receiving care and support)

Advocates offering limited support

Some participants said that advocates did not offer help with elements that they needed, such as completing paperwork to support a challenge.

Perceived lack of independence of the advocate

Some participants felt that the advocate was influenced by the local authority. In some situations it was clear that these advocacy services were provided by voluntary organisations funded by the local authority, while in others it was not clear if they were part of the local authority or external organisations.

‘The independent advocate is under their wing too, because they just tell her what to say and that's wrong, that's not independent.’ (EH11, Adult receiving care and support)

Lack of knowledge about advocacy

Participants did not necessarily know what advocacy was and said they were worried about having advocacy because they did not know what the advocate might say or do.

A poor outcome

In some situations, despite advocacy, the challenge did not result in the outcome that the participant wanted or led to a worse outcome, and that put participants off advocacy.

One participant was an advocate and highlighted difficulties in fulfilling their role, including lack of resource to proactively reach people, and the impact of COVID-19 on their ability to build a relationship for advocacy.

There were a few examples of positive experiences of advocacy. One participant described this in detail as: the advocate building a good relationship; the advocate raising issues clearly and straightforwardly; and the advocate checking in on how they were. In this case, the advocate was from a carers' organisation. Other participants echoed the importance of the advocate building a relationship and being available.

User-led advocacy by disabled people's or carers' organisations was described as helpful because of the knowledge and background awareness that the advocate brought.

One participant highlighted the importance of having an advocate for the carer as well as for the adult accessing care and support.

5. What people think would help to improve experiences of challenging decisions about adult social care

Participants told us about what they thought would improve the experience of challenging adult social care decisions about assessment, care and support and review. Participants in England and Wales gave similar suggestions. Specific points relating to Wales are highlighted. These responses are split into two areas: suggestions for people who use the social care system; and suggestions relating to local authorities. We highlight issues that relate to protected characteristics under the Equality Act 2010 and to other characteristics.

5.1 Suggestions to help people who use the adult social care system

Participants made a number of suggestions about how to improve experiences of challenging adult social care decisions. These related both to what they wanted for themselves and to what they thought local authorities could do to improve. There was some overlap between the two. Suggestions for people who use the adult social care system are as follows.

Access to information

Participants said it would help to have more straightforward ways to access information through websites, signposting, targeted information and information in different languages and formats. This included a suggestion to have dedicated advisers who know about entitlements to adult social care. One participant suggested having information from people who have been through the process.

‘Peer websites [would have been helpful] with all of the options, because there is one thing about the caring person, the person under care at home, and their needs, their multiple needs, but there is also support to be provided to the carer ... I wish there was one website with resources, signposted resources, with options out there, targeted information, thematic information to look.’ (EH03, Carer, Wales)

Support

Participants highlighted the need for additional support, including: advocacy; legal support; and peer support from grassroots or user-led organisations. One carer in Wales highlighted the value of groups where people could come together and share information. Participants raised the point that support needs to be independent and accessible. This would provide people who needed to challenge decisions with voice and influence.

‘I think there should be at least one service available in every locality which can help people not necessarily write the complaint for them, but assist them with the complaint, help them with the motivation and the wording and who to submit it to. I'm quite resourceful I have to say, but not everybody would know where to submit an official complaint or how to do it. So I think that's something that needs to be provided as well.’ (EH09, Adult receiving care and support)

5.2 Suggestions for local authorities

Participants made a number of suggestions about what local authorities could do to improve the experience of challenging adult social care decisions. Some of these reflect the suggestions set out in section 5.1; local authorities should provide clear, accessible information, set out clear expectations about what should happen in the adult care system and enable access to support. There were other suggestions that related to the way local authorities acted.

Professional capabilities

Participants said that people working in local authorities who make social care decisions and handle challenges need to have the capabilities – skills, knowledge and values – to be able to follow the law. They also highlighted the need for people to be committed to non-discrimination, including by being flexible in their decision-making, not making assumptions and having knowledge of each person's particular needs, impairments and conditions. Participants highlighted the importance of local authority staff who work directly with adults and carers being able to make decisions and being empowered by the local authority to do this.

Positive behaviours

Participants wanted staff in local authorities who made adult social care decisions to be proactive in responding to their needs and wishes by: overcoming barriers to engagement such as language barriers; contacting people rather than waiting to be contacted; preparing for discussions by finding out about the person; and having clear time frames.

Participants also wanted local authority staff to show the positive behaviours of consideration, listening, empathy, honesty and openness, and to work in partnership with people who use the system and trust what they say.

Transparency and accountability

Participants highlighted the importance of local authorities being transparent about what was possible and how decisions were made.

‘They are doing things behind our backs. They have to be open and honest. All they have to come out and say is, “We've got no budget.” Nobody ever says that. They just say it's us that don't need the need. They're not saying that; they're writing that we don't need the need. They're ignoring what we're saying.’ (EH23, Carer)

Participants said that there needs to be accountability for how people who make adult social care decisions follow the legal rules. Suggestions were for local authorities to: be clear about who makes decisions; have ways of overseeing and checking decisions; and hold people accountable for their decisions. A few participants suggested that if there is disagreement about a decision then an independent person (not from the local authority) should look at it. One participant said that if decision-makers were not following the law, then there should be consequences from their employer.

One participant proposed having a clearer, informal resolution process that would allow a more timely and proportionate response than making a formal complaint:

‘If something isn’t working, not have to have it be like this is a formal complaint, terrible territory, before you can justify allocating me to somebody else ... I’d like somebody that trusts me, and I can trust back, to advocate for my needs and present them in a way that is accurate. I think that’s really key.’ (EH32, Carer)

Resources

Several participants talked about the need for local authorities to have sufficient resource to make appropriate decisions in the first place and to respond effectively to put things right when a challenge identifies that this is needed. This included having enough resource to allocate the right practitioner who can build a good relationship with the adult or carer.

‘Disabled people, and their parent / carers, are not actually receiving basic human rights in terms of the services that are required and should be provided. There is only one reason; it’s resources, Central Government funding.’ (EH26, Carer)

‘The money is not there by the council to provide what people needed.’ (EH41, Carer, Wales)

5.3 Suggestions that were related to people’s characteristics

Participants told us that people facing particular barriers need a range of responses from local authorities to ensure that appropriate decisions are made and that people are empowered to challenge if needed. Participants highlighted the importance of local authorities:

- understanding and responding appropriately to disabled people or those experiencing particular impairments or health conditions
- making adjustments related to characteristics such as language and culture, for example in how information is provided, and
- making a particular effort to uphold the rights of people who may lack capacity to make a decision.

‘They need to look at a person and their individual needs and how it impacts on their environment and their relationships and everything else. There's loads of rhetoric that goes on through health and social care theory and practice, but in reality, it doesn't happen. People don't look at people that way, or they're not enabled to.’ (EH21, Carer, Wales)

‘They're applying too standard a model to every case ... It's just bang, bang, bang, and they're not really taking the person, the cared for, the cared for's family, the situation and the circumstances into account, which is a very unfeeling, inhumane way to do it really.’ (EH16, Carer)

One participant in Wales highlighted the importance of carers being recognised by all agencies at once so that they can get the necessary entitlements. The participant also stated that it would be beneficial for carers to be involved in local authority committees and for government representatives in social care to have caring experience.

6. Summary and conclusions

This research provides a rich picture of individual stories about adult social care decisions relating to assessment, care and support and review, and the experiences of challenging these decisions. The interviews provided participants' views of what had happened and also their views about what would improve things for themselves and others. The situations described were complex and diverse. Some stories took place over several years, and many situations were not yet resolved. Participants said that they wanted to tell their stories so that they could help to improve things for other people.

The research identified that there were diverse reasons why people were unhappy with adult social care decisions, there were negative effects experienced because of these decisions, there were multiple barriers to challenging decisions, the outcomes of challenges were mixed and the impact of challenging was often negative for participants. Experiences were affected by the characteristics of the participants and the way in which local authorities acted.

When individual members of staff were responsive and acted on complaints, this was helpful. Advocacy could be helpful, as could support from someone in a leadership position in social care in the local authority, from someone with legal knowledge or from an elected representative. In a minority of situations for these participants, challenges did lead to improvement.

Some participants highlighted the impact on other people who might face similar situations. They raised concerns about those who faced particular barriers to challenging, such as lack of knowledge or capacity.

The research points to a lack of consistency in how decisions are made and how challenges are responded to that can lead to unequal outcomes and impact. Participants proposed that this could be improved by providing people who use adult social care with clear information about their entitlements and processes and with support to navigate the system. They suggested that further improvements could result from ensuring that local authority staff have the right professional capabilities and demonstrate positive behaviours and that local authorities are transparent, accountable and have sufficient resources to enable good decisions to be made and to respond effectively to challenges.

The issues that came up reflect some of the issues that are known about the implementation of the Care Act 2014 and the Social Services and Well-being (Wales) Act 2014, and the known context of reduced local authority funding. Some participants' more recent experiences may have been exacerbated by pressure arising from increased demand and the COVID-19 pandemic. The recommendations from participants also reflect evidence of what is needed for the two acts to be fully implemented (see Braye and Preston-Shoot, 2016; Fernandez et al., 2020; Llewellyn et al., 2021 and 2022; Manthorpe, 2021; Think Local Act Personal, 2017).

The experiences of participants and their suggestions point to the importance of legal literacy among those who are involved in making adult social care decisions and handling challenges. Legal literacy involves sound knowledge of the legal rules, strong engagement with professional ethics and respect for principles of human rights, equality and social justice (Braye and Preston-Shoot, 2016).

'The Social [Services] and Well-being Act has been written for a reason. I've read that and I've read into – and it's a brilliant Act, but ... they're not acting as they should act, as the Act says they'll act.' (EH34, Carer, Wales)

Assessment, care and support and review are opportunities to promote equity and dignity. It is in everyone's interests that these elements of the adult social care system work well so that people can experience good decisions that promote their well-being and have positive experiences of challenge if they need to do this.

Acknowledgements

The Research in Practice team are grateful for participants' courage in telling their stories.

References

[Braye, S. and Preston-Shoot, M. \(2016\), 'Legal literacy in adult social care: Strategic briefing'. Dartington: Research in Practice for Adults \[accessed: 10 August 2022\].](#)

[Care Act 2014.](#)

[Equality Act 2010.](#)

[Fernandez, J., Marczak, J., Snell, T., Brimblecombe, N., Moriarty, J., Damant, J., Knapp, M. and Manthorpe, J. \(2020\), 'Supporting carers following the implementation of the Care Act 2014: eligibility, support and prevention'. London: London School of Economics and Political Science and King's College London \[accessed: 10 August 2022\].](#)

[Human Rights Act 1998.](#)

[Llewellyn, M., Verity, F., Wallace, S. and Tetlow, S. \(2021\), 'Evaluation of the Social Services and Well-being \(Wales\) Act 2014: Process evaluation \(GSR report number 02/2021\)'. Cardiff: Welsh Government \[accessed: 10 August 2021\].](#)

[Llewellyn, M., Verity, F., Wallace, S. and Tetlow, S. \(2022\), 'Expectations and experiences: service user and carer perspectives on the Social Services and Well-being \(Wales\) Act 2014 \(GSR report number 16/2022\)'. Cardiff: Welsh Government \[accessed: 10 August 2022\].](#)

[Manthorpe, J. \(2021\), 'The impact of the Care Act 2014: A summary of the research evidence'. London: NIHR Policy Research Unit in Health and Social Care Workforce, The Policy Institute, King's College London \[accessed: 10 August 2022\].](#)

[Mental Capacity Act 2005.](#)

[Nosowska, G. \(2020\), 'Embedding human rights in assessment for care and support: Frontline briefing'. Dartington: Research in Practice \[accessed: 10 August 2022\].](#)

[Social Services and Well-being \(Wales\) Act 2014.](#)

[Think Local Act Personal \(2017\), 'The Care Act 2014: Survey results: Exploring the impact of the Care Act on the lives of people with care and support needs. London: TLAP \[accessed: 10 August 2022\].](#)

[United Nations Convention on the Rights of Persons with Disabilities.](#)

[United Nations Principles for Older Persons.](#)

[Wellings, D., Jefferies, D., Maguire, D., Appleby, J., Hemmings, N., Morris, J. and Schlepper, L. \(2022\), 'Public satisfaction with the NHS and social care in 2021: Results from the British Social Attitudes survey'. London: The King's Fund \[accessed: 10 August 2022\].](#)

Appendix

Questions that we asked

Opening questions to get into the person's journey

Tell us a bit about yourself, who you are, what is important to you?

What is a good life like for you, what does good support look like?

About the person's journey

Tell us about your journey in getting and using social care.

Tell us about the points when things were working well.

Tell us about the points when things were tough.

Questions about specific points in the journey (how these relate to the EHRC inquiry online survey questions is indicated in italics)

What happened? (*What decision was made about assessment, care and support, review, reassessment; were the rules followed?*)

- When you needed some help, what happened?
- Did you get what you wanted?
- When did this happen?
- Who was involved?
- How did this happen? – How were you involved, what support did you have, what information were you given?

How did you feel about what happened? How did you feel about what happened at the time?

- Did you get what you wanted?
- What difference did that make in your life?
- How was it for other people?

What happened next? (*What challenge, if any, was made about assessment, care and support, review, reassessment; what enabled or hindered challenge; were the rules followed?*)

- What worked well, what didn't work for you?
- Did you try to change it? – Why?
- How did you try to change it?

- Did you get any help?
- What helped?
- What seemed to get in the way?

What happened in the end? (*Were the things that needed to be put right put right; were the rules followed?*)

- What did people do about it?
- Did it get sorted out?
- How did this happen? – Who changed things, what did they tell you, how long did it take?

How did you feel about what happened? (*What was the impact of the experience on human rights including health, how you feel, your choice and control over what happens to you, your relationships with others?*)

- How did you feel about what happened in the end?
- Did you get what you wanted?
- What difference did that make in your life?
- How was it for other people?

What should change? (*How can the rules be clearer and followed better?*)

- What do you think would have been better?
- Have you got any advice or ideas for the social service people about how to make it better?

A bit more about you (*What differences of experience are there for people with different protected characteristics?*)

- We already know a bit about you from when we arranged the interview. Can we ask you a bit more about yourself? This will help us identify how experiences are different for different people.

Contacts

This publication and related equality and human rights resources are available from [our website](#).

Questions and comments regarding this publication may be addressed to: correspondence@equalityhumanrights.com. We welcome your feedback.

For information on accessing one of our publications in an alternative format, please contact: correspondence@equalityhumanrights.com.

Keep up to date with our latest news, events and publications by [signing up to our e-newsletter](#).

EASS

For advice, information or guidance on equality, discrimination or human rights issues, please contact the [Equality Advisory and Support Service](#), a free and independent service.

Telephone 0808 800 0082

Textphone 0808 800 0084

Hours 09:00 to 19:00 (Monday to Friday)

10:00 to 14:00 (Saturday)

Post FREEPOST EASS HELPLINE FPN6521

© 2023 Equality and Human Rights Commission

Published February 2023

ISBN: 978-1-84206-860-1