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Thinks
Insight & Strategy

How care inequities shape social care experiences

July 2026

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About SCIE

The Social Care Institute for Excellence (SCIE) is an independent social care charity with deep experience of bringing partners and people with lived experience together to collaborate and innovate to improve people's lives (e.g. national government, DHSC, local authorities, care providers, academics, foundations). Working across social care, health and related services such as housing, for adults, children and families, we contribute to the development and implementation of better care, support and safeguarding at local and national level.

As we are not-for-profit, our income goes towards improving social care. We deliver four main offers, across all of which we support the DHSC annually:

- **SCIE Consultancy** – working with local and national organisations to identify and implement improvements
- **SCIE Insights** – research, evidence and policy insights to drive improvements and innovation, and influence national policy and practice
- **SCIE Training** – bespoke online or face-to-face learning and development, including safeguarding, co-production and strengths-based approaches
- **SCIE Resources** – guidance and tools to support best practice, co-production and innovation.

Co-production with people with lived experience of social care underpins and informs what we do, and with over 20 years' experience we bring a wealth of trusted, evidence-based expertise to work together to help transform care. Our staff – former practitioners in social care, researchers, experts in training – bring immense depth of experience and passion for the cause, based on frontline work, using the best available knowledge about what works in practice.

> "It's very conservative to say that the services are under pressure. It's more like it should be [at] breaking point."
>
> **46-65, Male, Dudley**

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Foreword

For too many people, getting social care means navigating a system that is confusing, fragmented and exhausting. That is an inequity in itself.

As national and local leaders consider the future of adult social care, including a National Care Service, equity must be at the heart of reform. But fairness cannot be judged only by whether services exist or people meet eligibility criteria. It must also be judged by whether people can find support, understand their options, influence decisions and sustain care without being worn down by the process.

At SCIE, we wanted to move beyond describing where inequities exist and understand how they are experienced in people's lives. Our Care Equity Evidence Hub has brought together what is known. This research takes the next step. Hearing the voices of people drawing on care and support and unpaid carers, we can understand how inequities accumulate across the care journey and how the system's structural and operational barriers add to the burden people face.

The findings offer powerful insights and suggest some practical solutions. Inequities rarely appear as a single barrier. Unclear information, repeated assessments, fragmented services, poor continuity and the need to keep asking, chasing and proving need can accumulate over time. For some, this leads to exhaustion, loss of trust and withdrawal from support.

The research also makes clear what equitable care looks like. People described good care as being listened to, known as an individual and supported through relationships built on trust and continuity. Co-production and relational care are not optional extras. They are central to a fairer system.

Our research about care equity is timely, and we expect the insights in this report to inform the design and delivery of a more equitable future social care system. For local services, the direction is clear: better information, named points of contact, continuity, culturally appropriate support and a skilled and supported workforce. For wider reforms, a fair system must work for all people who draw on social care, not just those who have money, confidence, digital skills, professional knowledge or family advocacy.

I am deeply grateful to everyone who shared their experiences, to SCIE's co-production network, and to Thinks Insight & Strategy for their research expertise and partnership throughout. This report gives us a basis for action. It challenges us to build a fairer, more relational adult social care system: one shaped with people, rather than done to them.

Baroness Glenys Thornton
Chair of the Board,
Social Care Institute for Excellence

01 Executive summary

Background and objectives

Adult social care plays a vital role in supporting people to live safely, independently and with dignity. However, experiences of care are not equal. Access to appropriate support, the quality of care received, and people's choice, control and dignity can vary significantly depending on personal circumstances, location, resources, health needs and how services are designed and delivered. The Social Care Institute for Excellence (SCIE) commissioned Thinks Insight & Strategy to conduct exploratory qualitative research to better understand how people drawing on care and unpaid carers experience inequities in adult social care in England. The research focused on exploring lived experiences of inequities, and how intersecting factors such as disability, ethnicity, gender, age, socioeconomic position and geography shape experiences and expectations, and what could support a more equitable and person-centred care system.

Methodology

The research used a multi-phase qualitative approach, combining expert input with lived experience engagement and co-creation. We engaged 50 participants across two phases of primary research: the first focused on exploring personal experiences of seeking and receiving care, and the second on ideas for improving fairness and access within adult social care.

Research was conducted with people drawing on care and unpaid carers across four local authority areas: Westminster, Dudley, North Tyneside and Wiltshire. These areas were selected to provide variation in geography, local service context and adult social care spending power. The sample included participants with a range of care needs, socioeconomic backgrounds, levels of digital confidence, ethnicities, ages, genders and types of formal and informal support.

Key findings

01 **Many perceive the adult social care system as complex and opaque.** Across the sample, participants describe uncertainty about eligibility, funding and provision. The effort required to understand and coordinate support has significant negative impacts on health and wellbeing, and, for some, leads to dropping out of the formal care system entirely.

02 **Wider narratives of overstretched services shape perceptions and expectations of adult social care.** Many participants situate their own experiences within a broader narrative of public services as underfunded and struggling. This serves as an explanation for experiences of poor care and leaves many resigned to inadequate formal care. However, it also leads to a profound fear that formal care funding could be taken away or reduced at any point.

03 **Perceived scarcity shapes how people understand their own needs, entitlement to support and sense of deservingness.** Many compare themselves with others they see as more deserving or more in need, and some describe feeling guilty, burdensome or reluctant to ask for help. It also contributes to more complex judgements about who is or is not "deserving" of care, including concern that some people may be misusing or taking advantage of the system and further adding to pressure on limited resources.

04 **Good care is strongly associated with being listened to, understood and involved in decisions, while poor care is associated with rigid and impersonal processes.** For many, moments that make care feel adequate or dignified come from individual interactions, often with frontline professionals: a quick response, a consistent carer, a professional who listens, or someone who treats them with kindness and respect. These interactions matter because care is personal and sensitive, and because continuity reduces the burden of repeatedly explaining needs.

05 **Informal care is important in filling gaps, but it is more than just compensatory.** Most receive a mix of different types of support, both by necessity and choice. Receiving informal care causes complex and conflicting emotions. For many, gratefulness and affection mix with guilt or even resentment.

06 **Participants recognise inequities, but most commonly understand them through the idea of a 'postcode lottery'.** These geographical differences are recognised as unfair, but are often accepted as an inevitable consequence of local funding pressures and service shortages. Inequities are therefore experienced through everyday realities such as long waits, inaccessible information, rigid eligibility criteria and the need to self-advocate, rather than understood as systemic disadvantages affecting particular groups. As a result, poor experiences are more often attributed to a "broken system" or bad luck, leaving many feeling disempowered rather than explicitly excluded.

07 **Access to good care is strongly shaped by financial means, location and the ability to navigate the system.** Some participants are satisfied with the amount and type of care they receive, particularly where they can pay privately, use direct payments effectively, or have strong informal support. Others struggle to access more or better formal care because of cost, long waits, unclear information, eligibility thresholds, digital barriers or the complexity of advocating for themselves. These barriers are especially acute for those with fluctuating, invisible, cognitive or mental health needs.

08 **Demographic and health-related inequities affect both access to care and the quality of people's experiences.** Participants from ethnic minority backgrounds describe language barriers, unmet cultural and religious needs, and expectations around family caring that can delay or complicate formal support. Older and younger participants both experience age-based assumptions, though in different ways. Women are more likely to describe guilt and burden in relation to needing care or providing it. People with poorly understood, fluctuating or invisible conditions often face disbelief, repeated proof of need and services that are not designed around how their conditions affect daily life.

09 **Inequities in care are cumulative and compounding, rather than driven by any single factor.** Structural pressures such as funding constraints, workforce challenges, fragmented services and weak accountability create the conditions in which other inequities play out. These then interact with geography, socioeconomic status, ethnicity, language, age, gender, disability and health condition. When these factors come together, participants often have less agency, fewer routes to support and more negative experiences of care.

What this research adds

This study adds to the evidence base by showing how inequities in adult social care accumulate across people's everyday experiences. Existing evidence identifies inequities linked to geography, socioeconomic position, ethnicity, age, gender, disability, health condition, digital access and wider system pressures. This research shows how these factors interact across people's care journeys.

The study challenges us to focus on equity not only as a question of who is eligible for care, but as a question of who can access, understand, shape and sustain support. Structural problems were often experienced personally, through guilt, low expectations, feeling like a burden, or withdrawing from support. Relational care mattered because being listened to, known and treated with dignity shaped whether care felt fair and trustworthy. Financial means also shaped not only whether people could access support, but how much choice, control and flexibility they had.

The discussion section in this report interprets these findings through five connected themes. It should be read not as a second set of findings, but as an explanation of how inequity is produced and reinforced: through barriers that accumulate over time, system pressures that are felt personally, the importance of trusted relationships, the work involved in navigating care, and the effect of financial resources on choice and control.

For policy, the findings suggest that reform should be judged not only by whether services are available or people meet eligibility criteria, but by whether people can find, understand, shape and sustain support. This has implications for national consistency, coordination, workforce stability, information and advice, regulation, data and co-production.

For practice, local authorities, commissioners and providers should reduce the work placed on people and unpaid carers. This includes providing clearer and more proactive information, named points of contact, better continuity and coordination, accessible non-digital routes, and culturally appropriate support. Assessment, review and complaints processes should also minimise repeated explanation and avoid requiring people to continually prove their needs.

These policy and practice implications are reflected in the priorities identified by participants:

- a named point of contact to help them navigate the complex system
- better continuity of carers to improve the quality of care and reduce the burden of having to explain one's needs
- clearer and more proactive information to ensure everybody is aware of their entitlements
- more consistent provision across areas to reduce the postcode lottery
- investment in the workforce to encourage greater professionalism and retention
- greater use of trusted community and culturally appropriate services to help reach more marginalised members of the community.

Underpinning these ideas is a clear desire for care that is shaped with people, rather than done to them. The discussion section develops these implications in greater detail and considers what the findings mean for local service improvement and wider adult social care reform.

02 **Background and methodology**

Background and objectives

The adult social care system plays a vital role in supporting people to live safely, independently and with dignity. However, experiences of care are not equal, and access to appropriate support can vary significantly depending on personal circumstances, location, resources and how services are designed and delivered.

Inequities within adult social care may be shaped by a range of intersecting factors, including disability, socioeconomic position, geography, ethnicity, gender, age, health needs and wider structural barriers. These differences can influence not only access to support, but also the quality of care received, feelings of control, and overall wellbeing.

The Social Care Institute for Excellence (SCIE) commissioned Thinks Insight & Strategy (Thinks) to conduct exploratory qualitative research to better understand how people drawing on care and unpaid carers experience these inequities in practice, and to identify opportunities to support a more equitable and person-centred adult social care system in England.

Thinks conducted qualitative research with those who are receiving care with the aim of understanding:

- how people drawing on care and unpaid carers perceive and experience inequities in adult social care provision – including access to care, quality of outcomes and experiences
- in what ways intersecting social identities – such as disability, ethnicity, gender, and socioeconomic status, and culture – shape people's experiences of adult social care, and what other factors may influence these experiences
- what informal strategies people drawing on care and carers use to manage or navigate gaps in formal social care provision
- how structural and systemic features of the adult social care system contribute to feelings of exclusion, disempowerment, or invisibility among people drawing on care
- how insights about people's lived experience inform the development of more equitable and person-centred adult social care policies and practices.

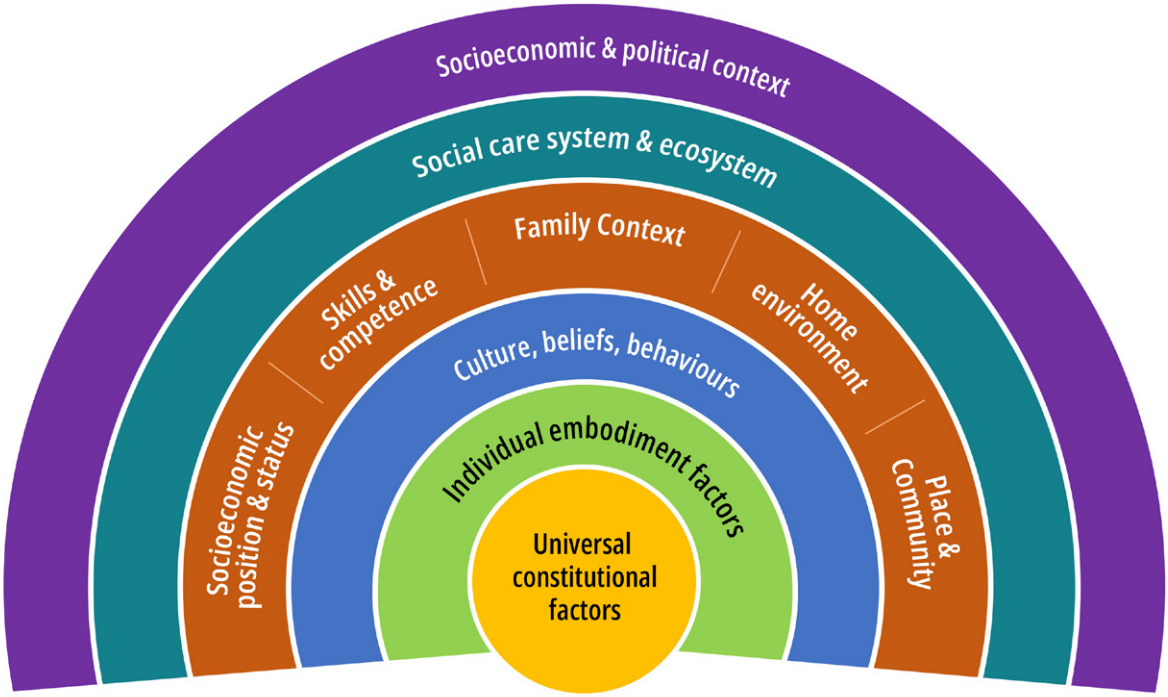
Defining care equity

Throughout this report, we use the term inequity to describe differences in access to, experience of, and outcomes from care that are unfair and avoidable. This aligns to SCIE's definition of care equity that states:

> "Equity in social care means the absence of unfair, avoidable or remediable differences in access to, experience of, or outcomes from care and support among groups of people - whether defined by social, economic, demographic or geographic factors, or by characteristics such as sex, gender, ethnicity, disability or sexual orientation."

SCIE's Dimensions of inequity framework [Figure 1], often described as a 'rainbow', presents a lens for understanding how layers of influence interact to shape people's access to, experience of, and outcomes from care. It shows personal characteristics (such as age, sex, and underlying health conditions) sit at the centre, surrounded by successive layers: individual factors and skills, culture and beliefs, family and community context, socioeconomic position, the design of the social care system itself, and finally the broader political and policy environment.

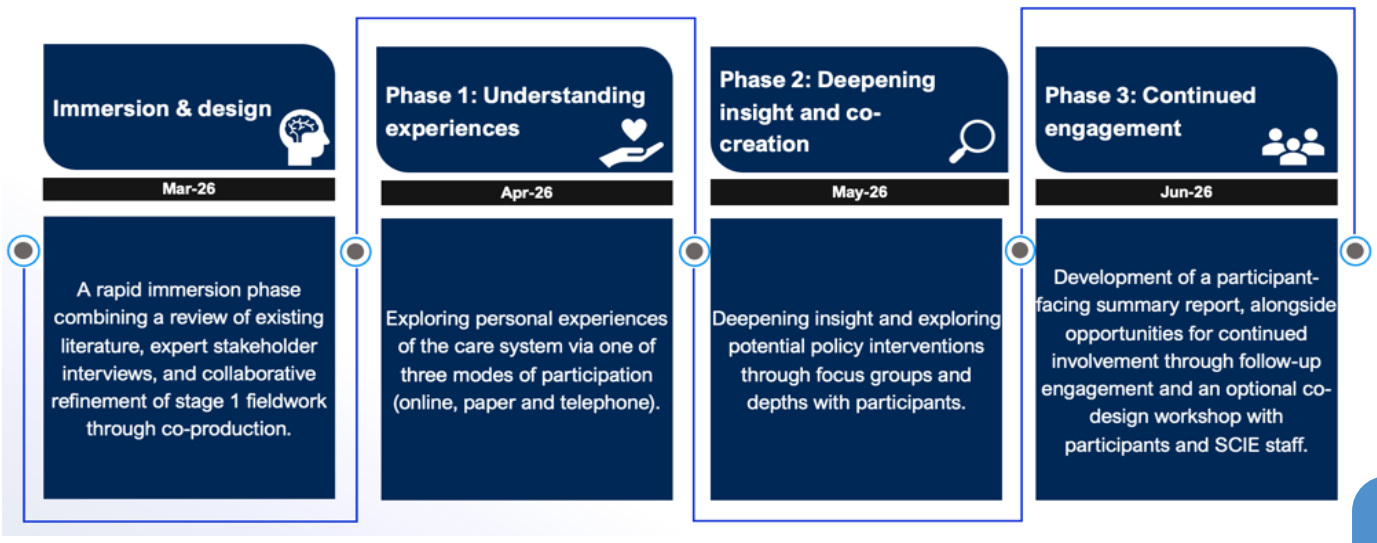
Figure 1: SCIE's Dimensions of inequity framework



Methodology

To address these objectives, we designed a multi-phase qualitative programme combining expert input, lived experience engagement and collaborative development to generate robust, in-depth insight into inequities within adult social care, set out in Figure 2 and outlined in detail below:

Figure 2: multi-phase qualitative research approach



Immersion and design phase: literature review and expert interviews

- An in-depth review was conducted of 10 recent and relevant sources to inform the sample design and Phase 1 fieldwork materials (see Appendix 1 for full list of resources).
- Findings were refined and consolidated through four expert interviews, drawing on perspectives from local authority leadership, academic research, social care policy and people with direct experience of the care system, before being taken into the first steering group meeting to co-develop materials for the next phase.

Phase 1: Understanding experiences
To understand experiences of care, a flexible multi-method qualitative approach was used, enabling participants to share personal and sensitive experiences in the way most comfortable to them:

- online activity between 7- 30 April 2026: 19 completions
- phone interviews from 9 April 2026: 7 completions
- 'offline' alternative to online community participation via email, from 9 April 2026: 27 completions.

Phase 2: Deepening insight and co-creation
To explore how experiences of care could inform potential policy interventions, participants were invited to reflect on findings from Phase 1, discussing key challenges identified and coming up with different ideas on how to improve fairness and access within adult social care:

- focus groups between 19-21 May 2026: 6 focus groups conducted with 24 participants
- phone interviews from 19 May 2026: 23 completions
- paired depth on 28 May 2026:1 paired depth with 2 participants.

Co-production Advisory Group

Throughout the programme, the project was guided by members of SCIE's Co-production Steering Group and wider co-production network. We worked closely with the project advisory group to ensure that co-production sat at the heart of the approach. Members of the group reviewed and shaped materials at each phase of the research and reporting, providing expert and lived experience perspectives to emerging findings, and ensuring that the programme remained grounded in the realities of those most affected by inequities in adult social care.

Sample overview

We recruited participants to a purposive sample specification using a mix of on-the-ground recruiters, partner organisations (e.g. Healthwatch) and snowballing. Recruitment was undertaken across four local authority areas identified through the literature review as offering meaningful variation in geography, local service contexts and adult social care spending power: Westminster, Dudley, North Tyneside and Wiltshire, allowing the research to explore how experiences of care may differ across local councils (see Figure 3).

The sample also includes participants from a range of socioeconomic backgrounds, with varying levels of digital confidence, differing care needs, first-generation migrants to the UK (including some whose first language is not English), and LGBTQ+ representation.

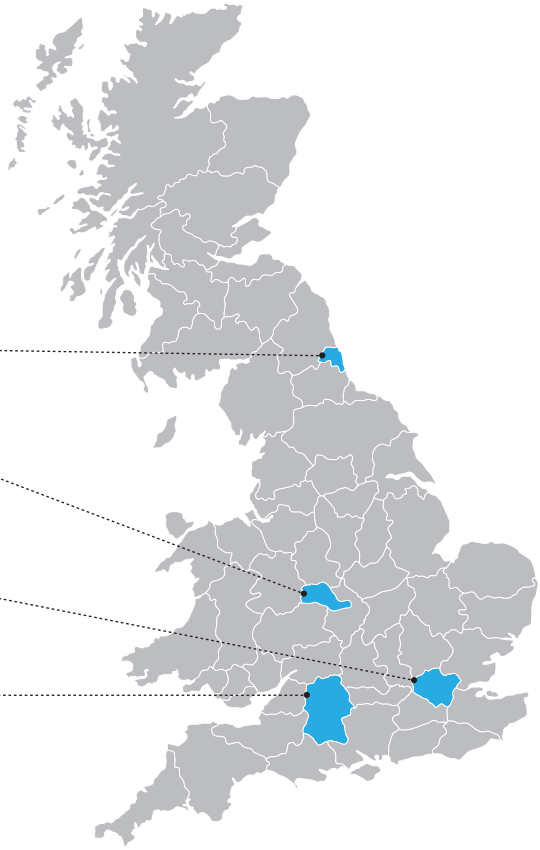
Figure 3: map of participant sample

North Tyneside Council: coastal location, mix of urban and rural, adult social care spending power risen sharply

Dudley Metropolitian Borough Council*: post-industrial urban location, with a recently cut social care budget

Westminster Council: urban location, spending power fallen sharply

Wiltshire Council: rural location, spending power recently fallen



Sample breakdown

Category	Criteria	Westminster	Dudley	North Tyneside	Wiltshire
	Total	14	10	11	14
Gender	Male	7	3	4	7
	Female	7	7	7	7
Age	18-45	5	3	1	6
	46-65	4	7	8	4
	66+	4	-	2	3
Ethnicity	White	6	6	10	9
	Ethnic minority	8	4	1	5
Type of care	Primarily formal care	10	3	7	6
	15+ hours of care per week	3	6	8	5
	Not receiving adequate care	3	2	-	4
	Primarily informal care	1	6	5	6
Support need	Mental health condition	7	3	7	7
	Physical disability	11	7	10	10
	Learning disability	-	-	1	-
	Neurodivergence	3	3	2	4
	Cognitive impairment	1	1	1	4

[1]Expanded to also include Wolverhampton and Solihull as recruitment in Dudley stalled.

03 Perceptions of the adult social care system

- **The adult social care system is perceived as complex and opaque.** Fragmentation, lack of transparency and services that do not communicate with each other leave participants uncertain about how to access care, who provides it and who is eligible.
- **Expectations of social care are very low.** Participants situate social care within a broader narrative of overstretched, underfunded public services.
- **The perceived scarcity of resources shapes how participants see their own needs.** Narratives about limited resources lead many participants to position themselves as less deserving than others.

The adult social care system in England is seen as opaque, even by its users. Its complexity and fragmentation make it difficult to understand what 'the system' is, or how it works.

Many participants find it difficult to define different aspects and actors of the system, and are more likely to think of the specific people they interact with – their GP, social worker or carers. Where participants do have a sense of a wider 'system', they often describe services that do not communicate with each other, based on experiences of being passed between agencies operating in isolation. This general sense of opaqueness leads to uncertainty about:

- how to access formal care and how decisions about eligibility are made
- how to seek additional support, e.g. if council-commissioned/funded care is insufficient
- who actually provides care (e.g. who pays vs. who commissions vs. who provides)
- how local and national benefits work together, e.g. interactions with pip,
- where the health service stops and the care service begins, and how the NHS and councils work together, with many conflating these different systems
- who is eligible for support.

Narratives of overstretched public services further contribute to perceptions of a system that is not functioning as well as it should – and contribute to low expectations of adult social care.

There are widespread perceptions, based on personal experience and anecdote as much as media narratives, of overstretched and underfunded public services in England. Whether it is health, education, criminal justice or adult social care, there is a strong sense that resources are scarce and, in some cases, services are close to breaking point.

In this context, expectations of the availability and quality of social care are very low. The system is widely described as not working for people drawing on care or those who provide care. Mostly this is attributed to a lack of funding overall, both at the local and national level (though most do not know how social care is funded). More specifically, participants also mention poor pay for carers specifically, which they feel leads to issues with recruitment and retention of high-quality staff and results in poor experiences of care.

> “Yes, it’s all got to do with the money...you’ve got a pot that’s overstretched.”
>
> **46-65, Male, Wiltshire**

> “I fear that my support will be taken away as funding gets tighter and tighter within local government.”
>
> **46-65, Female, North Tyneside**

Narratives of scarcity contribute to participants worrying about being a burden on the system.

Many participants are reluctant to present themselves as entitled to care, emphasising that they did not want to be a burden on already stretched services or suggesting that others are in greater need. This contributes to feelings of guilt or low self-esteem but can also bring up complicated emotions and considerations of who is and is not ‘deserving’ of support – and a sense that there are also those who may be misusing or taking advantage of the system (and contributing to greater scarcity as a result). This is often fuelled by mis- and disinformation about how social care and the wider benefits system work and who is entitled to support, including, for example misconceptions about entitlements among migrants and people seeking asylum.

> “I don’t want to become dependent. I don’t want to be somebody who’s totally reliant on services.”
>
> **46-65, Female, North Tyneside**

> “I don’t feel like I deserve it, you know. And there’s people who have nobody, whereas I’m lucky and I’ve got the 3 best people in my life sort of thing helping me, [otherwise] I couldn’t afford it.”
>
> **46-65, Female, North Tyneside**

> “Unfortunately, what happens is when these people come over illegally, they are given a team of multidisciplinary people that tell them and help them and give them exactly what they’re entitled to...people that have paid years into the system don’t get that service.”
>
> **46-65, Female, Wiltshire**

Case study 1

Ellie*, 83, female, multiple long-term physical health conditions, receiving formal support, City of Westminster

Ellie lives alone in an over-55s residential community and has experienced several significant health conditions over her lifetime, including multiple cancers, a heart condition requiring a pacemaker and a knee replacement. While she remains largely independent, she receives informal support from her daughter and pays privately for occasional household help.

Despite describing herself as fortunate compared with others around her, Ellie expressed feeling intimidated when interacting with formal support services. Applying for financial support left her feeling as though she was 'begging', while interactions with professionals often left her feeling talked down to because of her age. She felt that many older people receive less support than they need and described a broader perception that services are overstretched and unable to provide adequate care.

> "I think [the healthcare system] talk you down because of your age... it's like 'oh well, I've got another one of them coming in' sort of attitude, which is very degrading... I felt like I was begging [for help]."

04 Meeting care needs: formal and informal provision

- **Most participants rely on a combination of formal, informal and voluntary-sector support,** with each playing a distinct role in meeting clinical, practical, emotional and social needs.
- **The mix of support people receive is shaped as much by gaps in formal provision as by personal preference.** Family, friends and community organisations frequently fill unmet needs where statutory support is unavailable, insufficient or difficult to access.
- **When existing support arrangements do not meet their needs,** people often take on significant self-management and advocacy work, rely more heavily on informal networks or go without support altogether.

Most participants relied on a combination of formal, informal and voluntary-sector support. While these categories overlap in practice, each tended to serve a different function:

Type of support	Typical role	Main strengths	Main limitations
Formal care	Personal care, medication management, therapy, home adaptations and clinical support	Specialist expertise, funded provision, structured support	Often perceived as inflexible, limited, difficult to access, or poorly tailored
Informal care	Housework, meals, shopping, transport, childcare, companionship, advocacy and emotional support	Trusted, flexible and responsive	Can create pressure on family members and lead to feelings of guilt or dependency
Voluntary and community support	Information, advocacy, condition-specific support, social connection and community activities	Fills gaps in formal provision and provides specialist knowledge	Often dependent on awareness, referrals or local availability

Participants combine types of support out of both necessity and preference, leading to unique patterns and mixes of support across the sample.

Most participants described assembling a patchwork of support rather than relying on a single source. While some actively preferred support from family because it felt more personal, trusted or consistent with cultural expectations, its use was also often driven by necessity.

Informal care frequently filled gaps left by formal services, including long waiting lists, limited hours of support, cancelled appointments, unmet cultural or communication needs, and difficulties accessing statutory provision. Where formal support was unavailable or insufficient, family members often stepped in to provide additional care. Participants who funded or organised their own care generally reported greater flexibility and control, although cost and administrative burden remained significant barriers.

Access to support was often described as opportunistic rather than systematic, with people discovering services through hospital referrals, charities, community organisations, word of mouth or chance encounters (e.g. a leaflet at a GP surgery).

When existing support arrangements did not meet their needs, participants adopted a range of strategies to manage gaps in care.

- **Leaning on family and community:** family, partners and close friends are the primary safety net for most. Participants rely on these networks for personal care, meals, housework, transport, and admin tasks. Neighbours and community organisations (charities, Age UK, faith-based services) also fill gaps where formal care does not meet needs.

- **Going without:** many say they postpone or suppress their needs, often due to embarrassment, shame, or not wanting to burden others. This includes feeling shame when contacting services, or downplaying symptoms rather than seeking help. Some have stopped pursuing formal help altogether because the burden of chasing it is no longer worth it.

- **Digital and tech workarounds:** some use online searches to find providers and referral routes, apps and chat functions to avoid voice calls, online language translation, and generative AI for information and even emotional support late at night. However, digital exclusion remains a significant barrier with many describing themselves as “not computer savvy”, finding council websites difficult, and struggling with online forms.

- **Self-advocacy and coordination:** participants describe exhausting advocacy work for themselves such as repeatedly following up, calling different agencies, escalating cases, involving MPs, and organising or coordinating additional care. Some also take on coordination and management tasks themselves, such as translation and instructing care.

- **Self-management and wellbeing practices:** participants often mention pacing or “budgeting” their energy, managing their symptoms, and engaging in mindfulness, meditation, gardening, talking with others and prayer. Some pursue learning and purposeful activities to protect their mental health and fill time. Others might limit contact with services only to when “really needed” to avoid feeling overwhelmed.

- **Practical and work adaptations:** those who are in work have asked their employers to work from home, used PIP to fund care while continuing employment, or applied for Access to Work.

> “The support I receive is too little.
> I just cannot afford for a service every time I truly need help.”
>
> **18-45, Female, North Tyneside**

> “I am in control of [the support I receive] as I am paying it privately.
> However, I think that would be a limitation in the offer with the council,
> especially hearing that they are not consistent, and no one
> knows your exact needs.”
>
> **18-45, Female, Wiltshire**

Case study 2

Pushpa*, 46-65, female, severe physical health conditions, receiving informal support only, Dudley

Pushpa lives with arthritis, which can fluctuate significantly and make everyday tasks difficult to manage independently. She receives much of her day-to-day support from her daughter, who balances caring responsibilities alongside studying and raising a child. While she recognises the demands this places on her daughter, Pushpa strongly prefers receiving support from family rather than formal carers, particularly for more personal aspects of care.

For Pushpa, informal care provides reassurance, dignity, and a sense of comfort that she does not feel she could achieve through formal provision. Although she is conscious of the burden caring can place on loved ones, she describes family support as essential to maintaining her independence and wellbeing.

> “My daughter is 28, and [providing informal care] can be quite
> time-consuming, as she’s studying law and has a child of her own,
> and she’s chucking me in the midst of it all. You might think that’s
> a bit selfish when I could get home care [privately] to help me –
> but it’s the personalised care that I just couldn’t get.”

05 Experiences of the adult social care system

- **Any positive experiences of adult social care are shaped by individual interactions, not a sense that the system is functioning well as a whole.** Where participants experience positive outcomes, they tend to attribute this to trusted relationships, their own ability to choose (or pay for) their care and kindness from frontline staff rather than to the system functioning as intended.
- **However, more often, interactions with health and care professionals or council services are demoralising.** Participants describe a lack of personalisation and respect, for example being talked down to, treated as numbers, disbelieved, or even made to feel guilty for asking for help.
- **Negative interactions can cause real harm.** Challenging experiences with the system damage self-esteem, dignity and mental wellbeing. In some instances, negative experiences have led participants to withdraw from care altogether.

What good care looks like

Participants consistently described good care in relational rather than procedural terms. Feeling heard, maintaining independence and building trusting relationships were all seen as central to receiving adequate support.

Three characteristics are seen as particularly important.

- **Agency and control:** instances of good care are consistently described as feeling heard and receiving support that reflects individual needs and preferences. Participants who arranged their own care, either through direct payments or private funding, were often more likely to describe feeling in control, although direct payments were frequently seen as complex and poorly explained, with some recipients still unsure how to use them.
- **Maintaining independence:** participants valued support that enabled them to continue living independently without feeling overly reliant on others. The right balance of support was seen as protecting dignity, identity and self-worth. In some cases, this represents a barrier to seeking (more) formal care, due to fear that receiving too much care will increase dependence in the long run. For younger people in particular, personal care can feel like a threat to dignity.
- **Continuity and trust:** consistent relationships with carers, social workers and other professionals were highly valued. Continuity reduced the need to repeatedly explain circumstances, increased trust, and helped people feel known as individuals rather than cases to be managed.

Positive perceptions of care are usually rooted in these relational experiences – which is a key point of distinction between formal and informal care.

Participants often highlight individual professionals who showed flexibility, kindness or genuine understanding, describing these moments as exceptions within a system that otherwise felt impersonal, and contrast formal and informal support when describing these qualities.

Family members and close friends are frequently seen as providing a level of trust, familiarity and personal understanding that formal services struggled to replicate. For many, the value of informal care lies not only in the practical support provided, but in the sense of being known, understood and cared for as a person rather than a service user. However, these benefits were often accompanied by concerns about burdening loved ones. While informal care could enhance feelings of comfort and security, it could also create feelings of guilt, dependency and anxiety about the impact of caring responsibilities on family members.

> "My family and carer listened to what I needed, made sure I was comfortable, helped me with everything calmly and treated me with kindness and respect. What made it so good was that I felt understood, safe and cared for."
>
> **46-65, Female, Dudley**

> "I feel supported but not controlled and I don't have to keep feeling like an invalid. The support I have around me allows me to maintain dignity and independence while still getting the help I need, when I need it."
>
> **46-65, Female, North Tyneside**

> "It works well if they don't have new staff. I like existing staff and not open to new staff."
>
> **66+, Male, City of Westminster**

Barriers to experiencing good care

Many participants feel they have limited opportunities to build the trusting relationships they valued, but rarely blame staff for this.

Frequent staff turnover, changing carers and fragmented services mean relationships often have to be rebuilt from the beginning. Most participants do not blame individual care staff (even if some have had negative experiences with professional carers). Instead, professional carers are often described as "doing their best" in a system that does not respect or pay them fairly. While participants receiving professional care want staff to be in the job for the right reasons (i.e. not financially motivated only), there is a sense that better pay and greater professionalisation could lead to more retention and continuity.

For many, perceptions of a complex, opaque and overstretched system are reinforced by first-hand experiences that leave people feeling demoralised.

Journeys to receiving (more) care are often described as challenging, with participants reporting being:

- talked down to or disbelieved, including by their GP
- treated as a number or dismissed outright for not fitting into certain boxes
- made to feel guilty or judged for asking to receive care at all.

Low expectations, or experiences of dismissal, can also lead to delayed care seeking. Many have a sense that they will only get help once their needs are severe enough to meet relevant criteria, which can put them off engaging with prevention or early intervention. Once they have sought support, participants are then often left in the dark about why certain decisions have been made or what is available to them, with some only learning about support through informal networks rather than official communication.

> “We honestly would not know how to access support or ask for help without feeling embarrassed or problematic. The GP and hospitals are so busy [and] can’t wait to discharge you.”
>
> **18-45, Female, Wiltshire**

> “We don’t really have the confidence to try and ask for help too early because we just get told we don’t need that help.”
>
> **46-65, Female, Wiltshire**

> “The local council don’t want to know me. They think I’m an attention seeker.”
>
> **46-65, Female, Wiltshire**

The impact of negative experiences

Negative or challenging interactions with the care system leave many participants feeling worse than before, putting them off asking for more care or following up on previous requests for help.

Many participants describe damage to self-esteem, dignity and psychological wellbeing – including isolation, low mood, exhaustion, and in some cases severe mental health crisis. Where participants feel they have not received a decision that will meet their needs, they describe lacking the energy or knowledge to contest decisions, compounded by anxiety and embarrassment about asking. In some cases, it leads participants to withdraw entirely after repeated rejection, finding the effort of chasing services not worth it. All of this can prevent participants from seeking help when they need it and exacerbate feelings of guilt.

> “I’m just a National Insurance number to His Majesty the King... I am not a human being.”
>
> **66+, Male, City of Westminster**

> “The burden to keep sending emails and following up with things is not worth it. So, I stopped many years ago.”
>
> **46-65, Female, City of Westminster**

> “A long time ago I spoke to the council to have a care needs assessment, but they also wanted to do a children’s needs assessment at the same time and despite that being against the law as it is about my needs, it was anxiety provoking for me and so I stopped the process.”
>
> **18-45, Female, Wiltshire**

In the context of poor experiences with formal care, participants frequently describe mixed emotions about relying on informal care – and are aware of the costs to their family carers.

While support from family is often associated with love, trust and continuity, many worry about the financial, emotional and practical impact on those providing care. Concerns about carer burnout, career sacrifices and the possibility of losing a primary source of support are common. As a result, some participants delay asking for help or attempt to manage alone, even when additional support would have been beneficial.

Case study 3

Sophia*, unpaid carer and advocate for her brother-in-law, Richard*, 46-65, male, with autism and complex support needs, receiving informal support, North Tyneside

Sophia has supported her brother-in-law Richard, who is autistic and non-verbal, for over 30 years. Because Richard cannot communicate his experiences directly, Sophia's understanding of his care is shaped largely by trust, observation and relationships with professionals.

While she speaks positively about some individual staff members and advocates, Sophia describes a system that is often "difficult to understand and navigate". She remains confused by funding arrangements, struggles to understand why certain decisions are made, and feels much depends on the quality of individual services and staff rather than consistent standards across the system.

For Sophia, positive experiences stem from relationships with people who know Richard well and take a genuine interest in his wellbeing. However, concerns about staffing pressures, communication between services and a lack of transparency mean trust is often relied upon where direct oversight is not possible.

> **"Richard* does not welcome his carers into our house. He would physically shout at them and try and throw them out. So, we can't really watch what's going on [with the help he receives]. We just kind of rely on trust, people taking notes, and the whole care plan being reviewed."**

06 How intersecting identity factors shape experiences of care

- **Participants recognise and experience inequities, but they rarely describe them as structural.**
- **The impact of challenges with the system** (e.g. lack of resources, bureaucratic complexity) are commonly felt. These challenges **create the conditions in which all other inequities play out.**
- **Geography, financial means, demographic characteristics and health conditions all shape experiences of care.** For example, those who can afford to pay privately for care report more personalised experiences than those who can't; both younger and older participants report negative experiences from age-based stereotyping.
- **Inequities compound one another.** When multiple pressures converge – structural, geographic, demographic, and health-related – they interact in ways that reduce agency and makes participants' experiences of care worse.

How domains of inequity interact

Participants recognise and experience inequities, but rarely describe them as structural inequity – with the exception of the "postcode lottery".

Participants widely perceive the social care system as unfair, often describing a "postcode lottery" in which access to support depends on where someone lives. However, these differences are rarely understood or described as structural inequities. Instead, poor experiences are more often attributed to a "broken system" – connected to the sense that all public services are struggling – or simply bad luck. Inequities are lived through everyday experiences such as long waiting times, unmet needs and difficulties navigating services, but were seldom named as systemic disadvantages. As a result, participants tend to feel disempowered by the system rather than actively excluded from it.

> "Some councils are more affluent than others, and so they have more to use for that budget."
>
> **46-65, Female, Dudley**

> "Each council has a certain budget and everybody's trying to cut costs, and it seems sometimes that people that are most vulnerable in society, they are the ones that suffer more."
>
> **46-65, Female, Dudley**

The research reveals that inequity in social care is not produced by any single factor.

Instead, it is the cumulative result of multiple, overlapping conditions — structural (i.e. funding and workforce), geographic, socioeconomic, demographic and health-related — that interact and compound one another in ways that make some people's experiences consistently and significantly worse than others.

The sections that follow move through five domains of inequity, identified across the research, ordered to reflect how these factors build on one another.

- **Structural and systemic outward conditions** – such as the funding constraints, workforce pressures and bureaucratic processes, which the majority of users experience and shape how all other inequities play out.
- **Geographic inequity** – which shapes almost every aspect of how participants experience care, including what services exist, how well-funded they are, how easy they are to navigate.
- **Socioeconomic factors** – determine how participants experience those geographic and systemic realities, with cost emerging as one of the most significant barriers to accessing formal care.
- **Demographic characteristics** – including ethnicity, age, and gender, intersect and shape how participants access care and are treated by the system.
- **Health condition and disability** – shape not just what support someone needs, but whether they are believed, how easily they can access care, and how they experience it when they do.

Structural and systemic drivers of inequity

Participants' experiences are shaped not only by who they are, but by the system they are navigating. Structural and systemic factors create the conditions in which all other inequities play out.

Participants across the research identified a consistent set of systemic factors that underpin inequity:

- **Lack of resource:** participants describe experiences of long waits, reduced provision, and services operating under sustained pressure. When statutory provision cannot meet need, participants are pushed toward self-funding, reduced support, or going without.

> "The waiting lists are long. There's just not enough support, and you never know what kind of support you're going to get."
>
> **18-45, Female, Wiltshire**

- **Workforce shortages and time pressure:** staff shortages, high turnover and low pay are felt to produce rushed, task-focused visits and make continuity difficult to sustain. Additionally, participants highlight gaps in staff skills and training with many describing care that fails to meet specific condition needs or to feel genuinely person-centred.

> "They should increase the pay [of carers], and employ more staff, because the workload can sometimes be too much. If they have extra hands, more workers, [the carers] can give them the adequate care needed."
>
> **18-45, Female, Wiltshire**

- **Fragmentation, bureaucracy and poor coordination:** NHS services, local authorities and care providers are seen to frequently fail to communicate with one another. Participants feel that managing their care across multiple services is a significant burden. Instead of experiencing well-coordinated multi-disciplinary teams (MDTs), at the moment, participants are likely to have to do this coordination themselves. In a way, the system has outsourced MDT coordination onto the patient and their family. Additionally, inflexible eligibility thresholds mean that accessing support requires sustained effort which many find difficult.

> "You have to constantly repeat yourself, justify why you're asking [for help] constantly, explaining time and time again... they make you feel so demoralised, like you're asking for something you shouldn't be asking for."
>
> **46-65, Female, Dudley**

- **The lack of accessible information** about what support exists reinforces inequities. Participants describe not accessing entitlements such as PIP, social work support, or community services not because they do not need them, but because they do not know they exist. The expectation that participants will identify their entitlements, and advocate persistently on their own behalf is a key driver of inequity, impacting those with the least capacity to do so.

> "Nobody in the healthcare system ever said, 'you should apply for this', or have a think about applying for PIP. Nobody tells you these sorts of things... [The healthcare system] does not need to organise anything, they just need to make you aware that [the support] is available."
>
> **46-65, Female, Wiltshire**

- **Weak accountability and oversight:** a recurring frustration is a lack of accountability that participants experience at every level of the system. Poor regulation and monitoring of care agencies, difficulty changing providers when care falls short, and weak or unresponsive complaints processes mean that problems go unaddressed even when they are clearly identified.

Whistleblowing concerns are not acted upon, and feedback mechanisms feel performative with participants questioning whether data collected about their experiences leads to any real change.

> “Every care is completely different with how they treat you. There are people that will just come, and you’re just a number for them to tick; they just do the basics and leave. There is never continuity in terms of care, [and] that is a little bit frustrating, [because] the standard of care is not always the same.”
>
> **46-65, Female, City of Westminster**

Geographic impacts on care

Participants repeatedly use the term “postcode lottery” to describe how access and quality of care depend on where you live.

Urban and metropolitan areas (London in particular) are seen as having more and better provision than rural ones. For example, specialist services and access to newer treatments are seen to be more available in urban and better-resourced areas. A north/south divide is also assumed, with services in northern locations perceived as less well-funded.

> “More funds are usually given to people in London than the outside London.”
>
> **18-45, Male, Wiltshire**

However, in our sample, urban provision is not straightforwardly better. Participants in Westminster describe services that exist in greater number but are stretched, with less capacity for person-centred care.

> “I’ve got friends that live further out and they seem to get a lot better attention than lot a lot more than people that live inner London.”
>
> **66+, Female, City of Westminster**

Outside social care provision, those living in rural areas do experience additional challenges.

Rural participants in Wiltshire, describe isolation, lack of transport and limited voluntary sector as key features of their experience.

> “She gets so much better care there because she’s in London. And down here in the West Country, we seem to be out in the sticks.”
>
> **46-65, Female, Wiltshire**

In some specific cases, participants have fallen between the cracks at council boundaries which worsens experiences of care.

Cross-boundary funding rules can leave people unable to access social services in the area where they actually live. Moving home also disrupts continuity, leaving people waiting long amounts of time for assessment results after relocating.

> "The doctor came with a handwritten note, [and] said, 'we can't help you, you need to go to the hospital, to the crisis team'... I live on a border between two towns, and I just got turned away."
>
> **46-65, Female, Dudley**

> "Every local authority, every local NHS, every local care agency, all of them have their own sets of rules, budgets, and responsibilities."
>
> **46-65, Male, Dudley**

Case study 4

Hamza*, 46-65, male, physical and mental health conditions, receiving informal support only, Wiltshire

Hamza lives in Wiltshire and manages several long-term health conditions, including heart failure, chronic kidney disease, vertigo and depression. While he values the healthcare he receives, he feels access to wider support is heavily influenced by where a person lives. In particular, he describes significant differences in the availability of charities, community organisations and practical support services between London and Wiltshire.

For Hamza, geographic inequities are about the uneven distribution of local resources and support networks. He feels people living in areas with stronger charity and community infrastructure have more access to support. He notes that this division might be caused by varying local funding decisions, and that this overall contributes to a sense of a 'postcode lottery' within the system.

> "I've got friends who are in London, and there are many more charities there and they seem to have more [support available]. It's not the North-South divide, [but] the Central-West divide; it's about where the assets are, and how many charities are available."

Socioeconomic impacts on care

Socioeconomic inequities have a substantial impact on care, with cost the main barrier to accessing formal care. Those who can afford to pay privately report better, more flexible, and more personal experiences of care – but with a strong sense that this is neither fair nor sustainable.

Private care is described as more responsive and continuous, with staff who have time to engage and the ability to shape support around fluctuating or complex needs. For those with rare conditions or nuanced requirements, financial means can be the difference between feeling understood and going without.

However, for participants in this position, there is a sense of being penalised for having saved and of paying for something that should be a right. This is particularly true for those who are less affluent and feel the impact on their savings more acutely. Participants in this position describe having to cut back on 'nice-to-haves' and even some essentials like heating.

> "If you have more disposable income as well, you can perhaps obviously pay for additional care, and then clearly that's going to help on top of what you may get through the NHS or otherwise."
>
> **46-65, Male, Wiltshire**

> "I worked up until I was sixty-nine, paid all my taxes and did everything, [but] unfortunately, money doesn't last forever. Any savings that I had are disappearing very quickly, and they don't seem to want to help the elderly."
>
> **66+, Female, City of Westminster**

Those who use publicly funded care have a less personalised experience of care.

Long waits for NHS and council-arranged care are linked to anxiety and low mood, and the absence of flexibility or continuity – compared to what money can buy – is felt acutely. Those without the means to supplement statutory provision describe feeling isolated and, in some cases, hopeless. However, those with council-funded care also describe feeling grateful for not having to pay for their care.

> "I am grateful for what I do have, because I do get a direct payment through which I've been able to get the private personal assistant. So I appreciate that I do have a lot more than some. But there are massive holes in things."
>
> **46-65, Female, North Tyneside**

Demographic impacts on care

Across the research, there is clear evidence of how multiple and intersecting identity and demographic factors shape access, quality, and feelings about care. These inequities are particularly evident across ethnicity, gender and age.

Ethnicity

Ethnicity is a significant driver of inequity – affecting both access and the quality of care. Participants from ethnic minority backgrounds highlight ethnicity driven inequities across three key areas:

1. **Language barriers** consistently affect participants' ability to apply for care, navigate complex systems, and advocate for their needs. Participants describe breakdowns in communication between service users and carers as a particular source of tension, leaving people confused and unable to express what they need.

> "My dad's suffering from dementia and they've got carers coming in for him. And when they first started, I mean, the carers that were coming in, [my dad] didn't know what he was doing or what he was saying and he was talking to them in Gujarati, and [the carers] were talking to him in English, and he was just getting so confused. So, I think maybe they should do a little bit of background work and try and send people that can speak the language."
>
> **66+, Female, City of Westminster**

2. **Recognition of religious and cultural needs** – including diet, worship, and comfort with animals – is central to person-centred care. Participants describe experiences where these needs go unrecognised, with care that falls short of basic dignity.

> "[My carer] Susan understands I like to go to the temple. But [my other carer] Peter, he says he [will not take me] to the temple. He does not understand that it is very important for me to go out."
>
> **66+, Male, City of Westminster**

3. **Cultural norms and expectations of family caring** can mean "outsiders", including professional carers, doing intimate personal care can feel unacceptable, delaying participants from seeking formal support.

> "To have a carer in the house, in our community it's not a done thing. Because in ours it's meant to be family helping you, not outsiders."
>
> **66+, Female, City of Westminster**

Geography shapes how ethnicity intersects with care experiences.

Participants from ethnic minority backgrounds in more diverse urban areas (particularly London) describe meaningfully better access to culturally matched support than those in rural or less diverse locations. Where there are larger minority communities, there is greater likelihood of finding carers who share a language, understand cultural or religious needs, or can draw on local community and faith infrastructure.

> “If you are in an area where there are not many ethnic groups around it might be a difficult scenario. Say for example, some Romanian or Polish guy or lady has to go to an Indian person, and both of them don’t speak proper English, it becomes a little bit of an issue, and that can happen more in a remote areas than in an area where there are more ethnic groups around.”
>
> **66+, Male, Wiltshire**

Age

Age shapes experiences of social care inequity in distinct ways. However, older and younger participants often face the same underlying barriers but experience them differently.

Two patterns in particular cut across both groups: age-based stereotyping that leads to people not being seen as individuals, and service models that are not designed around people's actual lives and needs. The table below illustrates how these shared barriers play out differently depending on life stage.

Barrier	Older people	Younger/working-age people
Age-based stereotyping	• Feeling talked down to, treated as a number, assumed to be passive recipients of care • Undermines dignity and leaves people feeling unseen	• Reluctance to seek help and feeling judged • Assumed to be coping, disbelieved, or told they are too young to need support • Delays to diagnosis and assumptions that some are 'too young' to have certain conditions • Barriers to access and need goes unrecognised
Service models not designed around real lives	• Short-term care plans and time-limited reassessments are mismatched to needs • Fails to reflect irreversible, deteriorating conditions and requires people to repeatedly re-prove needs that are not going to change	• Services designed without working patterns, parenting responsibilities, or life-stage transitions in mind • Employment is viewed by the system as evidence of coping

> "When you go for hospital appointments or things like that, because of your age, you're just a number, you know, [it's just] 'we won't do this and we won't do that'."
>
> **66+, Female, City of Westminster**

> "I feel like a barrier is, because I'm younger, then the assumption is, well,' I can just get on with it'. And I do try, but that doesn't mean my life couldn't be made easier."
>
> **18-45, Female, Wiltshire**

> “But it’s difficult to explain because they see you as, ‘she’s working, she’s okay, she doesn’t need any support’. And you’re kind of stuck when you have a bad day and you have no support system coming.”
>
> **46-65, Female, City of Westminster**

Digital exclusion disproportionately affects older participants, many of whom lack access to devices and digital skills, or simply prefer human contact.

Participants stress that as services increasingly move online it creates a structural barrier for older and digitally disengaged people when applying for, managing and communicating about their care.

> “You need to have an email address and be okay with email and the internet to do just about anything these days. And my mum, who’s 83, I’ve tried teaching her, but she can’t seem to take it on board; she doesn’t want to be communicating across screens and emails and things like that. She much prefers to speak to somebody.”
>
> **66+, Female, Wiltshire**

Gender

Inequities in social care experiences across gender are more deeply embedded within caring structures, with women more likely to face additional barriers.

- **Guilt and fear of being a burden** shape how women experience needing care. Across the sample, women are more likely to internalise their needs as an imposition, both on partners who become carers and on the care system. Meanwhile, men tend to have higher expectations of formal service provision from the system. This can delay women from seeking support or advocating for themselves.

> “I think there’s a lot of stigmas around needing care as an adult... if you are disabled, you are [seen] as a bit of a burden and that’s not true. [However], I am a great advocate for myself and my children, but I’m a terrible advocate for myself.”
>
> **18-45, Female, North Tyneside**

- **Family caring is strongly gendered:** wives, daughters, and mothers are most often the default providers of hands-on care, frequently filling gaps left by formal services. Participants describe how care gaps threaten paid employment, and the physical demands of caring fall on whoever is available, regardless of capacity.

> “A lot of time I had to rely on my wife to be that person who is the anchor to support the mobility side of things, heading to work, getting to the nearest station and stuff like that. Because the care package that I should have had wasn’t as forthcoming.”
>
> **18-45, Male, City of Westminster**

Case study 5

Bhuvi*, 46-65, female, severe physical and mental health conditions, receiving both formal and informal support, Dudley

After contracting COVID in 2021, Bhuvi developed long COVID, leaving her with fatigue, brain fog and memory difficulties. She has since been diagnosed with fibromyalgia and perimenopause, and her mental health has deteriorated significantly, leading to her being signed off work as a nurse and eventually having her NHS contract terminated. On difficult days, she describes being unable to get out of bed.

Most of Bhuvi’s day-to-day support comes from her husband and children, who help with personal care, household tasks and mobility. She also funds a private carer to come twice a week, though she is acutely aware of the financial cost this place on her family: “that money that he’s spending on getting the carer in, that could go towards the household stuff”. This financial pressure has been compounded by a devastating scam in which she lost £26,000 of savings, which she describes as making “everything 100 times worse”.

For Bhuvi, declining health has fundamentally changed her role within the household. Previously independent and working as a nurse, she now relies heavily on her husband and children for personal care and day-to-day support. Needing this level of support at 48 carries a particular sense of guilt and embarrassment, which she links to expectations around independence, caring and womanhood. She describes feeling uncomfortable relying on others for intimate care. However, despite her professional background as a nurse, she would not know where to start with social services, and nobody has ever proactively asked whether she needs more support at home.

> “Within a year, my health has dipped so much, physical and mental health, that makes me feel very, very guilty that I’m putting on my husband so much. And I’m becoming a burden on him and my kids.... The money he’s spending on getting the carer in, that could go towards the household stuff.”

Health condition impacts on care

The nature of someone's health condition or disability shapes not just what support they need, but how easily they can access it, whether they are believed and how they experience the care they receive.

Across the research, several challenges are shared by participants regardless of condition type, however, how these are experienced varies significantly depending on the nature of someone's diagnosis.

The following barriers emerge consistently across the research, cutting across condition type.

- **Proving need:** participants across all condition types describe having to repeatedly justify their circumstances to assessors, professionals, and services before support is considered. The burden of proof is experienced as exhausting and demoralising.
- **Fluctuating and invisible conditions being misread**: assessments conducted on 'good days' fail to capture the variability of daily experience, leaving participants under-supported for harder days. This is felt acutely across physical, mental health, cognitive, and neurodivergent conditions.
- **Lack of continuity:** frequent changes in carers and social workers undermine trust and require participants to restart relationships and re-explain their health and care needs repeatedly.
- **Fragmentation between NHS and social care:** participants across all conditions describe services that do not communicate with one another, placing the burden of coordination on individuals and families.
- **Communication and access barriers:** phone-only access, complex forms and digital-first processes create barriers that affect people differently depending on their condition but are a shared significant obstacle.

> "I think sometimes if you get a prejudiced assessor or somebody who doesn't believe what you're going through, or they see you on a very good day and their perception of your illnesses [is not] what the reality actually is. It needs to be what you're saying and not necessarily what they are seeing on that particular day. Because like with myself, some days I'm okay, I'm able to get downstairs, I'm able to make myself breakfast, but other days I'm not able to do anything."
>
> **46-65, Female, Dudley**

Within these common challenges, the research surfaces distinct experiences by condition type.

- **For participants living with physical health conditions (particularly mobility related), experiences cluster around access, equipment and the quality of personal care received.** Participants with physical disabilities can experience challenges with accessing essential home adaptations and equipment (such as wet rooms, stairlifts, rollators). These are often critical to daily functioning but subject to long waits, bureaucracy or self-funding, with availability shaped by postcode as much as need. Eligibility thresholds mean many are turned away before they reach support, told they do not fit into existing "boxes" or refused on an initial phone call.

> "You have to try and work out who's actually dealing with what, and what aspect. For example, to get a wheelchair, I can apply directly to the wheelchair authority, but they then turn around and say, "well, your doctor's not signed it off, go back to your doctor". [It is] simple things like that. Or, you're entitled to a self-propelled wheelchair, but because you can walk 2 steps and that's their assessment, [but] the doctors are saying something else completely."
>
> **46-65, Male, North Tyneside**

- **Participants living with conditions that are not immediately visible or poorly understood face challenges around the need to explain and justify a reality that others cannot see.** Participants with invisible and lesser-known diagnoses (such as neurodivergence, arthritis, chronic fatigue or fibromyalgia) describe being frequently met with disbelief or unfamiliarity within the care system, with the legitimacy of their condition itself called into question.

> "When I was on cancer treatment, I was on Universal Credit and PIP, and just having to explain what chronic fatigue means, which nobody understood... The council didn't really grasp this. It's just constantly back and forth trying to convince people this is a real thing."
>
> **46-65, Female, City of Westminster**

- **Mental health needs interact with services in particularly challenging ways, with stigma and inflexible processes sometimes actively worsening participants' wellbeing.** Participants describe being dismissed as 'attention seekers', with phone-only access creating a specific barrier for those with anxiety. When support is delayed or inaccessible, escalation to crisis can follow.

> "When they're not listening to me, I just feel like I'm a burden sometimes. My crisis point is when I keep telling them over and over again until I get a breakdown."
>
> **46-65, Female, Wiltshire**

- **For participants with cognitive impairments, communicating, remembering and navigating systems are major barriers to receiving good care.** Participants with cognitive and speech impairments highlight the access requirements for phone calls, complex forms and the expectation of consistent recall as placing significant strain on people whose capacity may fluctuate. Many participants describe withdrawing from processes that ask too much of them.

> “I have a mild comprehension learning difficulty, and that wouldn’t necessarily be picked up, or the fact that I need support with processing things sometimes at the time or sometimes after, especially if it’s like emotional in topic. So, it’s not always obvious because of my presentation. And therefore, I end up quite misunderstood because there’s assumptions that, you know, I’ll be able to speak to someone or advocate for myself when actually that is not always correct.”
>
> **18-45, Female, Wiltshire**

07 Pathways to equity

Participants identify 6 ideas that could better support people's care needs

01 **A single, named point of contact is the most consistently and strongly supported solution**
02 **Continuity and consistency of carers**
03 **Greater national consistency in funding and provision**
04 **Clearer, more proactive information about available support**
05 **Investment in the workforce**
06 **Greater use of community organisations and culturally appropriate services**

Alongside their experiences of the system as it currently operates, participants discussed a wide range of ideas for how social care could better meet people's needs and address some of the established challenges driving inequity. The ideas discussed below are set out in order of support.

01 A single, named point of contact supported by shared records

A designated care coordinator, someone who knows the person, understands their needs, and can navigate the system on their behalf, is seen to reduce the burden of repeated explanation, help people access services they might otherwise miss, and provide stable support in a complex system.

> "Having somebody who is a named person, like your single point of contact, is great because you don't have to have that rigmarole of looking around trying to find the right person to get through to. You've got a particular person, the person who you're able to rely on getting that information that is required. So, I think that's really, really useful. Especially for those people that are needing the service more than others."
>
> **18-45, Male, City of Westminster**

Similarly, participants support greater integration between health and social care, with shared records that mean people are not required to repeat their story every time they encounter a new service or professional.

> "I think it's got to start with hospital assessments. And then a group of people from each individual agency are representing that particular client. And then they will meet before any care package is put in place, and they said, 'this is what the person needs, this is what we've got available' so every single agency is on the same page."
>
> **46-65, Male, Dudley**

02 Continuity and consistency of carers

Being supported by the same professionals who know them, understand their needs, and have had time to build a relationship, is described as transformative when it happens, and as a significant challenge when it does not. A consistent care team will also better allow for preventative support, so that people do not have to reach crisis point before help becomes available.

> “To have the same carer come in, I think that helps, because then the carer will know the patient, and they can form a relationship, form a bond. That would help because then I do find that when you know the carer, you will work with them rather than against them, and that would make everybody’s life much easier.”
>
> **66+, Female, City of Westminster**

> “I think definitely if people had more say over their care was organised and the support was offered earlier, um, it could prevent a lot of more advanced care being needed.”
>
> **18-45, Female, City of Westminster**

03 Greater national consistency in funding and provision

Fairer distribution of resources between councils, and between rural and urban areas, is seen as essential to addressing some of the deepest structural inequities. Participants also raise broader concerns about affordability and the sustainability of a system that increasingly relies on people’s ability to pay privately when statutory provision falls short.

> “More money spent in all areas [and] they [should] have the same budgets. Don’t just give one area a certain amount of money, make sure every area gets the same budget. Have a controlled area where, say, one national area gets the same as another area.”
>
> **46-65, Male, North Tyneside**

04 Clearer more proactive public information about eligibility, and how to access help

Simple, step-by-step guidance (e.g. through GPs, community settings, leaflets, and social media) is recommended to help people to understand the system and access support.

> “Have all the information that you need available. Maybe it’s measured in a leaflet or a book, in book form, from your local doctors or any chemist. [They] could just give a step-by-step information about what you need and how you go about setting all the care and care and things you plan up.”
>
> **46-65, Male, North Tyneside**

Alongside this, participants want more responsive and accessible communication channels which are flexible and tailored to different needs and preferences.

> “Maybe a dedicated 0800 telephone central call centre will be able to put you in the right direction if you have any issues or problems.”
>
> **18-45, Female, City of Westminster**

> “I struggle with phone calls to professionals. And so, on my notes with the social care, it says ‘contact me by email’, but it doesn’t happen. Just having people communicate in the way you want would be massive.”
>
> **18-45, Female, North Tyneside**

05 Investment in the workforce

More care staff, better pay and stronger training are needed, including condition-specific skills and, equally importantly, the empathy and relational qualities that make care feel human rather than transactional. Participants feel this will address the workforce pressures that drive rushed care and lack of continuity.

> “I think the training [carers] get is ‘infection control’, just basic manual handling and safeguarding. But they need a bit more specialised training, and more pay.”
>
> **46-65, Female, Wiltshire**

> If the carers were trained better, yeah, they would know how to look after elderly people, not just walk in, make a cup of tea, and walk out.
>
> **66+, Female, City of Westminster**

06 Greater use of community organisations and culturally appropriate services

Community and voluntary sector organisations, such as libraries and faith groups, are recognised underutilised assets that are often trusted by communities. Participants describe them as natural points of contact for people who would not otherwise seek help, offering navigation support, social prescribing, trusted relationships and outreach into communities that statutory services struggle to reach.

> I know a lot of communities have their weekly sessions in their community hall. Even if somebody went and talked about all what's available, what's not available, what you can do and how you can do it, who you can get in touch with. That will be just amazing.
>
> **66+, Female, City of Westminster**

Participants also call for culturally and linguistically appropriate services including language-matched carers, access to interpreters and translation technology, and outreach delivered through trusted community settings. Addressing this requires deliberate investment in workforce diversity, cultural competence training and proactive outreach to communities least likely to engage with the system on its current terms.

> Everybody has different needs, so it should be tailored to people's needs and their belief, their culture, their way of life.
>
> **18-45, Female, Wiltshire**

Additional consideration: earlier preventative support, but urgent needs come first

Participants broadly support the idea of earlier, preventative support, arguing that acting sooner would stop people deteriorating, avoid crisis and reduce demand on the system.

> If something is caught early, then it's better. [...] if help can be offered earlier when the person asks for help, it's better than waiting for things to get worse.
>
> **66+, Female, City of Westminster**

This is felt particularly among participants with mental health conditions, who directly link the absence of early intervention to reaching crisis point, describing a system that waits for deterioration before acting.

> “There are people who have mental health issues whose lives are basically in danger because of how they’re feeling, but there’s never that urgency with mental health things. It’s always, oh, wait a little bit longer, try this, try that, phone up.”
>
> **46-65, Female, Wiltshire**

However, overall, participants overwhelmingly see prevention through the lens of a system that is already unable to deliver basic care and meet the needs of people currently in crisis, and are sceptical that meaningful prevention is possible without first addressing that gap. Participants caution that prevention must not come at the expense of those with urgent, current needs, and several argue the first step must be addressing existing pressures.

> “I would say that would definitely help but it is not at the expense of cutting down somewhere where need is desperately required and urgent.”
>
> **66+, Female, City of Westminster**

08 **Discussion**

This research set out to explore how people drawing on care and support, and unpaid carers, experience inequities in adult social care. The findings show that inequity is not only shaped by who people are, where they live or what support is available locally. It is also shaped by how the care system is organised, how easy it is to understand, and how much power people have to influence the support they receive.

SCIE's Dimensions of inequity framework (see Figure 1 Section 1.1) provides a useful lens for interpreting these findings. The framework shows how different layers of influence, including individual circumstances, family and community context, socioeconomic position, the design of the social care system, and wider policy and political conditions, can interact to shape people's access to, experience of, and outcomes from, care and support. This study supports that framing and adds further lived experience insight into how these layers interact in practice.

Participants rarely experienced inequity as a single barrier or one-off decision. Instead, inequity was often experienced through a series of smaller frictions that accumulated over time: unclear information, uncertainty about eligibility, fragmented services, repeated explanation, long waits, limited flexibility, poor continuity and the need to advocate for support. These pressures affected many participants, but they were not experienced equally. They interacted with factors such as income, health condition, disability, age, gender, ethnicity, language, digital access, confidence, family support and previous experiences of services.

The cumulative inequity figure below (see Figure 4) builds on SCIE's Dimensions of inequity framework by showing how these barriers can build across different stages of the care process. It illustrates how structural pressures can affect each stage, from finding information and seeking assessment through to receiving support and requesting changes. It also shows how people's personal circumstances and resources can shape their ability to respond at each point. Where people have fewer resources to draw on, each stage can become harder, increasing the risk of unmet need, declining wellbeing, greater reliance on unpaid care, withdrawal from support, or crisis.

This is one of the main contributions of this research. It connects evidence on unequal access, local variation, financial means, demographic inequities and system pressures with the lived experience of trying to get, shape and sustain care. It shows how inequities already identified in the wider evidence base are experienced at person level, and how they can reduce people's agency, choice, control, dignity and trust.

The discussion is structured around five key themes.

01 Inequities are cumulative rather than isolated

02 Structural inequities are often internalised rather than recognised

03 Relational care is central to equitable care

04 Moving through the system is itself a source of inequity

05 Financial means shape agency, not only access

Taken together, these themes suggest that care equity cannot only be understood through differences in eligibility, provision or service availability. It also needs to be understood through people's ability to find support, understand decisions, influence the care they receive, and maintain dignity, independence and trust throughout their experience of adult social care.

01 Inequities are experienced as cumulative rather than isolated

Existing evidence

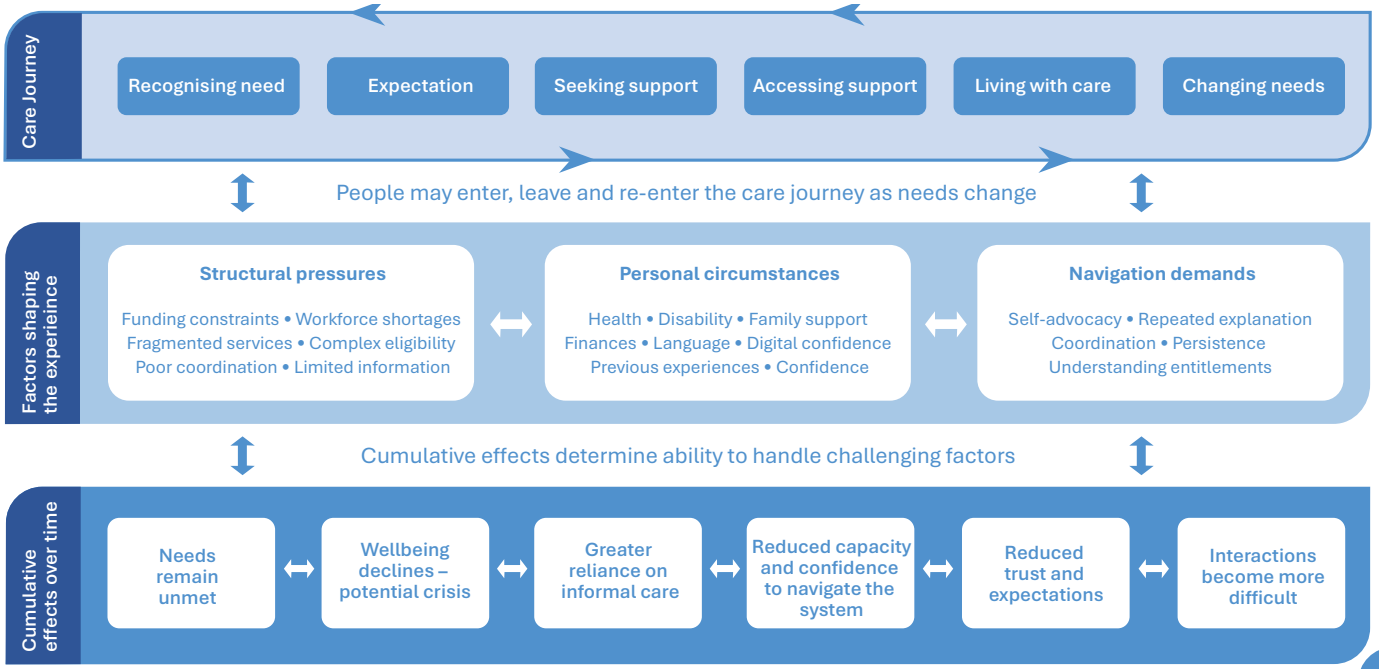
Existing UK evidence shows that inequities in adult social care are associated with geography (Gray et al. 2018), socioeconomic position (Slaughter et al. 2025; The Health Foundation 2026), disability (Ramsey 2022; Slaughter et al 2025), ethnicity (Hussein 2022; Tawodzera et al 2025), age (Johnson 2022; Sadler 2019) and structural features of the care system (Chang, 2022). SCIE's Care Equity Evidence Hub reflects this by organising evidence across key topics such as geographical inequities, financial inequities, workforce and underserved populations, while also recognising that inequities often cut across these categories (SCIE, 2026c). Appendix 2 describes the topics included on the Care Equity Evidence Hub further.

Wider national evidence similarly documents local variation, chronic underfunding, waiting lists and staffing pressures. However, much of this literature tends to describe inequity through separate domains of disadvantage, rather than through how those disadvantages are encountered cumulatively through people's journeys into and through care.

This research adds

This study adds a more process-based understanding. In line with SCIE's Dimensions of inequity framework (Figure 1), and reflected in the cumulative inequity figure included below (Figure 4), participants rarely experienced these as separate forms of disadvantage. Instead, inequity emerged as an accumulation of small barriers encountered throughout their journey into and through care including difficulties finding information, delays in access and assessment, repeated explanation, uncertainty about decisions, poor continuity and the ongoing work of coordinating support. These pressures were shaped by structural conditions, including fragmented services, workforce shortages, opaque eligibility processes and inconsistent information, but they were not felt equally.

Figure 4: diagram showing the cumulative impact of inequity in social care



These challenges then interacted with participants' individual circumstances, such as their health condition, financial resources, confidence, social support, language or cognitive capacity. Those with fewer personal resources found it progressively harder to navigate the system, advocate for themselves and access appropriate support. In that sense, this research shows that inequity in adult social care is not simply intersecting; it is often cumulative and compounding, with each barrier increasing exposure to the next.

Health evidence helps to reinforce this interpretation. Healthwatch (2023) has shown that people experiencing financial hardship face greater barriers not only in accessing care, but also in being listened to and involved in decisions, while UKHSA (2025) analysis shows how deprivation, geography and ethnicity combine in patterns of poorer health outcomes. What this research contributes is similar insight within adult social care: it connects established domains of inequity with the lived experience of moving through a fragmented system, and shows how disadvantage accumulate across different stages of the care journey rather than appearing only at isolated points of contact.

This research has also demonstrated the need for nuance when looking at structural divides such as 'urban vs. rural' or 'north vs. south'. For example, rural areas may have fewer voluntary and community assets, while large cities may have more services but less person-centred capacity, and cultural matching may be easier in diverse urban areas but still not reliable.

Implications for policy and practice

The findings from this study suggest that improving equity is not simply about addressing individual disparities (for example, geographic variation or digital exclusion) in isolation. Resolution also requires reducing the cumulative friction people encounter throughout their care journey by simplifying navigation, improving coordination between services, reducing administrative burden and intervening earlier before disadvantages compound. Greater awareness by policymakers and practitioners of the cumulative effects of inequities should help guide decisions for system and service reforms, and the targeting of resources to address them.

02 Structural inequities are often internalised rather than recognised

Existing evidence

The wider UK evidence base already shows that structural disadvantage in health, welfare and care is often mediated through institutional processes that affect how legitimate people feel when seeking support. Recent national reviews have found that poorly coordinated services, repeated retelling of need, unclear rules and weak communication do not only delay access; they also generate fear, exhaustion and disengagement.

A Health Services Safety Investigations Body investigation into care coordination for people with long-term conditions found that patients and carers were left feeling anguished, exhausted and guilty, and that some disengaged from services altogether when the effort of navigating the system became too great (HSSIB, 2025).

In the disability benefits system, the interim report from the Timms review of Personal Independence Payment concluded that the current process is experienced as dehumanising and burdensome, and can contribute to withdrawal from work and wider social participation (DWP, 2026). The Sayce review on Carer's Allowance Overpayments found that hidden or unclear rules, conflicting advice and administrative complexity left carers in the dark and unfairly penalised for failures in the system rather than failures of their own (DWP, 2025).

Evidence from social care and related systems suggests that complexity and administrative demand can disadvantage people whose circumstances make self-advocacy harder. Grant et al. (2023) argue that social care systems can be difficult to navigate and may place unrealistic administrative demands on autistic people. Within the current system, autistic adults may receive personal budgets to organise and manage their own support. However, the administrative and organisational responsibilities associated with coordinating care can be particularly challenging for individuals who experience difficulties with executive functioning. Consequently, the system may inadvertently disadvantage those with the highest levels of support need.

Similarly, policy analysis conducted by the Institute for Public Policy Research (IPPR, 2019) suggests that removing financial barriers could improve access to social care and reduce uncertainty for individuals seeking support. A shift towards a more universal model of care could make the system simpler and more transparent, while reducing the administrative burden associated with financial assessments and eligibility testing.

Research on unpaid carers also shows how the design of support systems can create insecurity and complexity. Slaughter et al. (2025) report that many unpaid carers experience financial strain linked to the design of Carer's Allowance. Key concerns include strict earnings thresholds and administrative complexity, both of which can discourage labour market participation and create financial insecurity.

Evidence on racial and ethnic inequities also shows how structural barriers can affect access to support. Ahmed et al. (2024) highlight persistent racial inequalities in access to dementia services. People from Black and other minoritised ethnic communities are under-represented within dementia services and often access support at a later stage, frequently during periods of crisis. Identified barriers include limited awareness of available services, language and literacy challenges, stigma, and difficulties navigating health and social care systems.

Wider children's social care evidence also shows how unequal treatment can arise through institutional assumptions as well as overt discrimination. Allen et al. (2021) examine how inequities in child protection can emerge through subtle and often unintentional forms of racism. The authors argue that, even when practitioners consciously reject discriminatory beliefs, professional decision-making may still be influenced by underlying assumptions and stereotypes. This can result in unequal treatment and poorer outcomes for Gypsy, Roma and Traveller children, highlighting the need for greater awareness of structural and institutional biases within child protection services.

In summary, this evidence shows how structural inequities can be produced through complex systems, unclear entitlements, administrative burden, stigma, discrimination and unequal treatment. However, the adult social care evidence is less developed on how people make sense of these experiences when they do not use the language of inequity. Much of the existing evidence identifies unequal access, discrimination or administrative burden, but says less about how these conditions are absorbed into people's feelings of deservingness, legitimacy, confidence and willingness to keep engaging with services.

This research adds

This study shows that participants rarely described themselves as experiencing structural inequity, even where their experiences clearly reflected wider systemic disadvantage. Instead, they made sense of these experiences through highly personal narratives: not wanting to be a burden, believing others were more deserving, feeling embarrassed to ask for help, or reading poor treatment as bad luck rather than as a feature of how the system operates. In that sense, structural inequities were often experienced psychologically rather than politically. System failures were translated into personal feelings of guilt, shame, low expectations and self-doubt, which in turn reduced confidence to seek help, appeal decisions or remain engaged with services. That pattern is visible across the study findings, particularly in participants' accounts of feeling demoralised, judged or burdensome, and in examples where repeated rejection or bureaucratic strain led people to stop pursuing support despite continuing need.

This is an important addition to the evidence base because it helps explain a dynamic that is not fully captured by accounts of access barriers alone. If people internalise system failure as a personal shortcoming, then inequity is likely to be underestimated by services: unmet need becomes quieter, complaints reduce, and withdrawal can be misread as absence of need rather than loss of trust. The finding therefore builds on the wider evidence base by showing not just that systems can be unequal, but that they can produce emotional responses which themselves become part of how inequity is reproduced over time.

Implications for policy and practice

Reducing inequity requires more than improving service provision. It also means creating systems that actively reinforce people's legitimacy, entitlement and dignity, reducing the emotional burden associated with seeking support and ensuring people are not left feeling responsible for failures within the system itself.

This includes clearer and more proactive information, less burdensome assessment and review processes, fewer occasions where people have to repeatedly prove need, and communication that does not leave people feeling blamed for the limits of the system. It also strengthens the case for trusted points of contact, advocacy and relational support, because these can help counter the tendency for structural problems to be experienced as personal failure.

03 Relational care matters almost as much as service provision

Existing evidence

Across the UK health and social care evidence base, person-centred care, continuity of care and co-production are already well-established markers of good care. Within SCIE's own care equity and practice resources, this is reflected in the prominence given to co-production, dignity in care, named social worker models and strengths-based approaches. SCIE's (2026a) dignity resources define good care in terms of recognising the individual, supporting self-respect, involving people in decisions, and communicating well. SCIE's (2026b) co-production resources similarly frame better care as something developed with people who use services and carers, rather than delivered to them. National Voices and Think Local Act Personal's (2013) narrative for person-centred coordinated care makes a similar argument, defining good integrated care from the perspective of people who need support from multiple services over time. Overall, this literature shows a strong consensus that the quality of relationships, communication and involvement matters to how care is experienced.

The workforce evidence also helps explain why relational care can be difficult to sustain in practice. High turnover, vacancies, low pay and time pressure can reduce continuity and limit the opportunities for workers to build trusting relationships with people who draw on care and support. Skills for Care's (2025) workforce evidence continues to show that adult social care faces significant recruitment and retention pressures, particularly in direct care roles. These pressures matter for equity because continuity, trust and personalised knowledge depend on a workforce that is stable, skilled, supported and valued.

Research by Krishnan et al. (2025) also highlights the importance of addressing workforce inequities as a key factor in delivering high-quality and equitable care. The report found that more than two-thirds of respondents had experienced or observed two or more forms of workplace inequality, most commonly relating to race or ethnicity combined with other characteristics. The study identified clear links between workforce inequities, staff wellbeing and care quality, with respondents reporting negative impacts on service quality, quality of care and interactions with people using services. More than 40% of respondents who experienced or observed race- or ethnicity-related inequities reported poorer interactions with patients or people using services. The research also found that inequities can affect staff willingness to speak up, progression opportunities and workplace culture.

From an equity perspective, these findings suggest that inequalities experienced by the workforce can translate into inequalities in the experiences and outcomes of people who use services. Where parts of the workforce are disproportionately exposed to bullying, discrimination, limited career progression, low pay or cultures that discourage speaking up, this may undermine continuity of care, trust and service quality. These effects may be particularly pronounced in parts of the care system already facing workforce, recruitment and financial pressures, including adult social care and smaller providers.

Taken together, the evidence shows that relational care is already recognised as central to good care. However, the adult social care evidence is less developed on how relational care operates as an equity mechanism. There is evidence that continuity, dignity, co-production and workforce conditions matter, but less evidence on how the presence or absence of trusted relationships can reduce or intensify inequities in people's everyday experiences of care.

This research adds

This study adds lived experience insight into why relational care matters for equity, not only for quality. Participants almost never described good care in terms of organisational structures or service models. Instead, they described it through relationships: feeling listened to, having continuity of carers, being known as an individual, exercising choice and maintaining independence. These relational experiences often appeared to buffer against wider structural pressures. Even where participants recognised the system as complex, overstretched or difficult to navigate, positive relationships with individual carers, occupational therapists, social workers or other professionals could make care feel more humane, responsive and trustworthy. Conversely, fragmented relationships amplified the effects of an already complex system. They increased the burden of repeatedly explaining needs, reduced trust in services, and made it harder for people to feel confident that support would reflect their circumstances.

The findings also connect workforce conditions to lived experience. Existing workforce evidence shows a sector under pressure from turnover, vacancies, pay constraints and workplace inequities. This research shows what those pressures can mean for people drawing on care and support: less continuity, less time to build rapport, more repeated explanation and fewer opportunities to be recognised as an individual rather than processed through a system. In this sense, workforce conditions are not separate from care equity. They help shape whether people experience care as relational, responsive and dignified, or as fragmented, impersonal and harder to influence.

Implications for policy and practice

These findings suggest that relational care should not be treated as an optional or softer dimension of adult social care. It appears to be one of the main ways people experience fairness, dignity and agency within the system.

Policy attention to access, eligibility and service supply remains important, but it is not enough on its own. Equitable care also depends on whether people have consistent, trusting relationships with workers who know them well enough to support choice, advocacy and personalised responses.

This strengthens the case for workforce investment, action on workforce inequities, continuity of care, co-production and commissioning approaches that give staff enough time and stability to build relationships. It also suggests that improving workforce experience and improving people's experience of care should be understood as connected equity issues, rather than separate agendas.

04 Navigating the system is itself a source of inequity

Existing evidence

Existing evidence already points to navigation as an important part of people's experience of health and care, even if adult social care literature does not always name it as a distinct dimension of inequity. Studies of access to health care have long shown that access is not only about whether services exist, but also about whether people can recognise their needs, identify appropriate services, present themselves as eligible, negotiate professional judgements and continue through complex pathways (Unwin et al, 2026; Dixon-Woods et al, 2006). This is particularly relevant to adult social care, where eligibility, funding, assessment, review and service provision can be difficult to understand.

Previous literature has also identified a range of barriers that shape people's ability to move through health and care systems. Health literacy research shows that people's ability to find, understand and use information is unevenly distributed, and that services can create barriers when information is too complex or not designed around people's needs (Rowlands et al., 2015). Digital exclusion research raises similar concerns, particularly as more information, applications, forms and routes into support move online. Digital access depends not only on having a device or internet connection, but also on confidence, skills, accessibility, affordability and trust (Good Things Foundation, 2024; NHS England, 2023).

> "There's no control. There's no control because it's like a lottery; some days you'll get support; some days it's get on with it yourself."
>
> **46-65, Male, Dudley**

The wider literature on treatment burden and administrative burden is also relevant. This literature shows that people with long-term conditions are often required to do considerable work to manage appointments, information, medication, referrals, communication between services and self-management expectations (Gallacher et al., 2011; Mair and May, 2014). Although much of this evidence comes from health care rather than adult social care, it is directly relevant to people who must coordinate care across health, social care, welfare, housing, voluntary sector and family support.

Recent UK evidence on care coordination and fragmented systems also shows that people with complex needs can be harmed when services do not communicate well or when responsibility for coordination is unclear. Evidence from dementia and long-term condition research highlights how people and unpaid carers often have to manage complex pathways, repeat information, chase appointments and bridge gaps between services (Giebel et al., 2024; Shand et al., 2023; Tawodzera et al., 2025). These studies point to navigation as a practical and emotional burden, particularly for people with cognitive impairment, fluctuating needs, language barriers, low digital confidence, limited family support or fewer financial resources.

Overall, the wider literature shows that navigation is not a neutral process. It is shaped by health literacy, digital inclusion, information quality, service fragmentation, care coordination and the personal resources people can draw on. However, the adult social care evidence is less developed in treating navigation itself as a mechanism through which inequity is produced.

The existing evidence tends to identify barriers separately, such as poor information, weak coordination or digital exclusion, rather than showing how these barriers accumulate across the whole journey into and through care.

This research adds

This study adds a clearer lived experience account of navigation burden as an equity issue in adult social care. Participants consistently described navigating adult social care as difficult, confusing and exhausting. However, the ability to overcome these challenges was far from equally distributed. Successful navigation depended not only on knowledge of the system, but also on confidence, persistence, financial resources, family support, language, digital skills, mental wellbeing and physical capacity. Participants with fluctuating conditions, cognitive impairments, poor mental health or limited support networks often found these navigation demands particularly difficult. This means that inequity did not arise only because services differed between places or groups. It also arose because the system expected individuals, and unpaid carers, to overcome complexity that many were least equipped to manage. The same eligibility process, online form, phone call, reassessment or complaints route could be more manageable for someone with time, confidence, advocacy and professional knowledge, and much harder for someone experiencing pain, fatigue, anxiety, cognitive impairment, poverty, language barriers or social isolation.

The research therefore extends the wider literature by showing how navigation burden is experienced in adult social care at person level. It shows how people can move from uncertainty, to repeated effort, to exhaustion, to withdrawal. In some cases, people stopped pursuing support not because their need had reduced, but because the work of navigating the system had become too difficult or demoralising. This suggests that system navigation itself functions as a social determinant of equitable care. People do not only need services to be available. They need routes into support that are understandable, accessible, coordinated and proportionate to the resources they have.

Implications for policy and practice

Improving equity requires reducing the demands placed on individuals to navigate the system independently. Participants' strongest recommendations, such as named care coordinators, clearer information, integrated records and proactive communication, can all be understood as ways of reducing navigation burden rather than simply increasing service provision.

This has practical implications for adult social care, whilst also influencing future policy reforms. Information and advice need to be provided in ways that people can understand and use, not only made available. Digital routes should be supported by non-digital alternatives. Assessment, review and complaints processes should reduce repeated explanation and avoid placing the burden of coordination on people and unpaid carers. Even a universal approach to assessment would have to acknowledge that a "one size fits all" solution may fail the equity test. People with more complex, fluctuating or intersecting needs may require earlier access to advocacy, care coordination or a trusted named contact.

The wider literature shows that health and care systems often require people to do significant work to secure support. This research shows why that work matters for care equity. When navigation depends on personal resources, the people facing the greatest barriers may also be the least able to overcome them

05 Financial means shape not only access to care, but agency within the care system

Existing evidence

The wider literature on social care funding has primarily focused on financial eligibility, affordability, incentives to save and the distributional consequences of requiring individuals to contribute towards their own care. Evidence has argued that the existing system exposed people to unpredictable and potentially very high costs, and recommended a cap on lifetime care costs alongside a more generous means test (Commission on Funding of Care and Support, 2011). More recent policy analysis has continued to frame reform around making adult social care fairer, more accessible and less financially uncertain, including through changes to the means test and proposals to limit unpredictable costs.

Mayhew's (2016) analysis of means-testing adds an important argument. The core point is that means-tested support does not affect people evenly. People with substantial wealth may be better able to self-fund, top up or purchase additional support. People with very low income or assets may qualify for more public support, although their choices may still be constrained by what is available locally. People with modest savings or assets can be left in a particularly difficult position: financially ineligible for some support, but not wealthy enough to sustain private care over time without steadily depleting resources built up across their lives. In this sense, means-testing can create a 'squeezed middle' who face uncertainty, asset depletion and difficult trade-offs between meeting care needs, maintaining independence and protecting future financial security (Mayhew, 2016)

The personalisation literature is also relevant. Personal budgets and direct payments were designed to increase choice and control by giving people more influence over how support is arranged. However, evaluations have shown that the benefits of personal budgets depend on more than the existence of a budget. They depend on the adequacy of the resource, the availability of suitable services, the support people receive to manage arrangements, and their ability or willingness to take on administrative responsibilities (Glendinning et al., 2008; National Audit Office, 2016).

This means that financial mechanisms intended to increase choice can still reproduce inequity if people have unequal capacity to use them, or if local markets do not offer suitable options. The existing evidence shows that money matters in adult social care in several ways: through eligibility, out-of-pocket costs, local market conditions, self-funding, and the ability to exercise choice through personal budgets or direct payments. However, the literature has tended to focus more on system design, affordability and distributional modelling than on how financial means shape people's day-to-day sense of agency, dignity and control within care.

This research adds

This study adds lived experience insight into how financial means shape people's agency within the care system. Participants rarely discussed means-testing in technical or policy terms. Instead, financial resources shaped the degree of control they felt able to exercise over their care.

Participants who could supplement or replace publicly funded care with private provision described greater flexibility, continuity and personalisation. They were better able to choose who supported them, when support was provided, and how care fitted around their routines and preferences. By contrast, participants relying solely on statutory provision often described having to adapt their lives around the system rather than receiving support designed around their needs and circumstances. These participants often described feeling caught between two systems: financially ineligible for additional public support but unable to sustain private care without steadily depleting savings that had taken decades to build. These participants described "rationing" their care, repeatedly negotiating between preserving financial security, maintaining independence, and meeting their care needs.

The inequity therefore extends beyond affordability alone. Financial means influence people's agency, dignity, independence and ability to shape the care they receive. In this research, the two-tier issue was not only that some people could buy more care. It was that they could buy more control.

Implications for policy and practice

The findings suggest that future discussions about charging reform and means-testing should consider not only who contributes financially towards care, but how funding arrangements shape people's experience of autonomy, choice and wellbeing.

A fairer system would reduce the gap in control between people who can privately supplement care and those who cannot. This means considering how public support can provide flexibility, continuity and personalisation, not only a minimum level of provision. It also means recognising the position of people with modest assets who may not be able to self-fund sustainably but still face substantial financial responsibility.

The findings also strengthen the case for clear information, advice and support around financial assessment, direct payments and care options. Without this, policies intended to increase choice and control may be easier to use for people with greater confidence, advocacy, family support or financial resilience, and less accessible to those facing the greatest barriers.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09 **Conclusion**

This research provides a detailed account of how inequities in adult social care are experienced by people drawing on care and support, and unpaid carers. Its significance lies not only in identifying different forms of inequity, but in showing how they interact and accumulate over time. Participants' experiences show that care inequity is not only about whether services are available. It is also about whether people can find support, understand their rights and options, influence decisions, build trust with professionals, and sustain care in a way that protects dignity, independence and wellbeing.

The findings support SCIE's Dimensions of inequity framework by showing how structural, social, economic, demographic, geographic and health-related factors interact in people's lives. They also extend the wider evidence base by showing how inequities are lived at person level. System complexity, local variation, workforce pressures, financial means, digital access, health condition, language, culture, informal support and confidence to self-advocate do not operate separately. They combine across the care journey, shaping people's access to care, the quality of their experiences and their sense of choice and control.

This matters for local services and for wider reform. Local improvement work needs to look beyond single barriers and consider the cumulative burden placed on people and unpaid carers. Clearer information, named points of contact, continuity of relationships, proactive communication, culturally appropriate support and stronger links with trusted community organisations are not only practical improvements. They are also equity measures, because they reduce the amount of personal resource needed to make care work.

The findings also have implications for national reform. A fairer adult social care system cannot be built only around eligibility, funding or service availability, although these remain central. It also needs to address the power people have to shape care around their lives. Participants' accounts point towards the importance of care that is relational, proactive and co-produced, with people drawing on care and unpaid carers involved in decisions about their own support and in wider decisions about how services are designed and improved.

Further research is needed to build evidence on what works to reduce inequities in adult social care. This should include evaluation of practical interventions, such as named care coordinators, improved information and advice, culturally appropriate outreach, advocacy, direct payment support, workforce interventions and models that improve continuity of care. Future research should also examine how different inequities accumulate over time, including for groups that remain less visible in adult social care data and evidence. Longitudinal, place-based and co-produced research would be particularly valuable, as it could show how people's experiences change as they move through assessment, care planning, service use, review and crisis points.

Overall, this research shows that care equity must be understood as both a system issue and a lived experience issue. Addressing inequity means reducing unfair differences in access, experience and outcomes, but it also means reducing the effort, uncertainty and emotional burden that people face when trying to get care. A more equitable system would not leave people feeling that they have to keep asking, chasing, explaining and proving need before support is made to work. It would be shaped with people, rather than done to them.

10 **Appendices**

Appendix 1: included literature to inform the sample design and Phase 1 fieldwork materials.

1. The Kings Fund (2024). What does the literature show about the factors associated with inequalities in social care? (online), available at: https://kingsfund.org.uk/library (Accessed April 2026 via Care Equity Evidence Hub, SCIE).

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Appendix 2: Care Equity Evidence Hub topics

SCIE Evidence Hub topics	
Underserved populations	Populations that face inequities in accessing and receiving care, resulting in poorer health outcomes compared to the general population. We have broken this down into groups by: Demographic Factors (age, sex, ethnicity, education), Social and economic factors and Health status. The definition of 'underserved' is context-specific, shaped by the specific circumstances, needs, and characteristics of the population. It highlights the importance of recognising and addressing the disparities in care provision to ensure equitable health outcomes for all individuals.
Financial inequities	This theme focuses on how economic factors influence access, quality, and sustainability of services. It examines the impact of funding disparities, variations in care costs, and the financial burden placed on individuals and families. Means testing, the role of self-funders, and differences in public versus private funding models all contribute to unequal experiences of care.
Geographic inequities	While distribution of services is a key focus, it also considers other factors that influence inequities and how they impact individuals and communities. These include variability in the presence of services, particularly between rural and urban areas, and the distances people need to travel to access care. Differences in the standard and reliability of care provided across regions, as well as regional variations in the costs of care and the financial burden on individuals and families, also play a role.
Use of technology in care	This theme looks at how digital tools, devices and systems are used across health and social care to support people who use services, carers and the workforce. It considers how technology shapes access, communication and the delivery of support. The evidence in this theme looks at who benefits, who is excluded, and how these patterns reflect broader inequities. Differences in local infrastructure, investment and digital skills across communities further shape the role technology plays in care. Workforce skills and confidence also affect how well digital tools are implemented and used in practice.
Neighbourhood Health	Neighbourhood health is an approach to improving health and wellbeing that brings care closer to where people live. It brings together local health, social care and community services through joined-up, multidisciplinary teams. These teams focus on preventing illness, identifying needs early and supporting people to stay well in their own homes and communities. A key aim is to reduce inequalities by directing greater investment and attention to communities with the poorest health outcomes and lowest healthy life expectancy. This includes using local data and equity-focused metrics to understand need, monitor progress and target resources proportionately.
Social Care Workforce	This topic focuses on the people who provide care and support across adult social care. It covers pay, working conditions, wellbeing, skills and access to training. It also looks at how recruitment, retention and workplace culture affect the quality and safety of care. Workforce issues are central to equity. Staff experience unequal pay, insecure contracts and uneven access to training and progression. International recruits face visa-related pressures, and staff from ethnic minority backgrounds report lower chances of career development. Differences in digital skills, supervision and leadership support also shape the opportunities available to staff across the sector.

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