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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.

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