

Experiences of inequities in social care: early messages from forthcoming SCIE research

A preview ahead of the full report

Care equity is the core theme for **SCIE's Co-production Week**, centred on the question: **who gets care?**

SCIE's wider care equity work is building shared language and evidence for the sector through the **Care Equity Evidence Hub**, co-produced definitions of care equity, and the **dimensions of inequity Rainbow Framework**.

As part of this work, SCIE commissioned **Thinks Insight & Strategy** to carry out qualitative research with people drawing on care and support, and unpaid carers. The research explores how inequities are experienced in adult social care, and how factors such as disability, ethnicity, gender, age, income, geography, health needs and wider system pressures, shape access, quality, choice, control and dignity.

The full report will be published in the coming weeks. This preview shares early messages from the research ahead of publication.

About the research

SCIE commissioned **Thinks Insight & Strategy** to carry out exploratory qualitative research with people drawing on care and unpaid carers in England.

The research used a multi-phase qualitative approach, combining expert input with lived experience engagement and co-creation. It engaged 50 participants across two phases of primary research. The first phase explored people's experiences of seeking and receiving care. The second phase explored ideas for improving fairness and access within adult social care.

Research took place 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 people with a range of care needs, socioeconomic backgrounds, levels of digital confidence, ethnicities, ages, genders, and types of formal and informal support. The value of the research lies in understanding how people make sense of their experiences and identifying recurring patterns that shape experiences of care and support.

What the early findings are showing

1. Care inequity is often experienced through system complexity

A strong early message is that the adult social care system can feel complex, opaque and difficult to influence.

Participants described uncertainty about eligibility, funding, provision and where to go for help. Many also described the effort involved in coordinating support, repeating their circumstances, following up decisions and trying to understand what they were entitled to.

This matters for care equity because the ability to navigate complexity is not equally shared. People with more time, confidence, digital access, family advocacy, professional knowledge or financial resources may be better placed to make the system work for them. Others may be more likely to accept unsuitable support, rely more heavily on unpaid care, go without or stop asking for help.

2. People may not use the language of inequity, but they describe unfairness clearly

People do not usually describe their experiences using policy language such as 'structural inequity'. They are more likely to describe feeling confused, dismissed, talked down to, worn down or unsure where to turn.

Many participants understood unfairness through the idea of a 'postcode lottery'. Others described a broken system, bad luck or low expectations about what adult social care could offer.

The language may be personal, but the pattern is systemic. Experiences of inaccessible information, rigid eligibility criteria, long waits, repeated explanation and difficulty challenging decisions can all point to wider unfairness in how care is accessed, organised and delivered.

3. Scarcity shapes expectations and feelings of deservingness

The research suggests that wider narratives about overstretched public services shape how people understand their own need for support.

Some participants worried that care could be reduced or taken away. Some compared themselves with people they saw as more in need. Some described guilt, reluctance to ask for help, or concern about being a burden on family members, professionals or the system itself.

These feelings matter. Low expectations, guilt and fear of being a burden can affect whether people seek support, how long they wait before asking, and whether they continue trying after poor experiences.

4. Inequities compound rather than act in isolation

SCIE's **dimensions of inequity Rainbow Framework** helps show how care equity is shaped by interacting factors across people's lives, communities, services, systems and wider structures.

The emerging findings support this. People's experiences were shaped by the interaction of factors including income, geography, informal support, digital access, ethnicity, language, faith, culture, age, gender, disability, health condition, workforce pressures, eligibility processes and service design.

These factors can combine in ways that reduce agency, choice, control and trust. This reinforces the need to understand care inequity as cumulative, rather than as a set of separate issues.

5. Good care is relational and shaped with people

The emerging findings also show that good care is strongly relational. People value being listened to, being known as an individual, having continuity and receiving support that reflects their needs, preferences and circumstances.

This links directly to choice, control and co-production. If people experience care as something rigid, impersonal or difficult to influence, then fairness depends on shifting power towards people drawing on care and unpaid carers.

Care equity is therefore not only about who gets support. It is also about whether people can shape that support, trust it and experience it as dignified and person-centred.

Why this matters for Co-production Week

The emerging findings point towards the need for a more equitable system built around relational, proactive and person-centred support.

They also show why co-production is central to care equity. If unfairness is partly about unequal power, then a fairer system must shift power towards people drawing on care and unpaid carers.

Co-production is not only about asking people for views. It is about sharing influence over how care and support are designed, delivered and improved. At the individual level, this means care and decisions are shaped with people, not done to them. At the service and system level, it means people with lived experience helping to shape information, access routes, assessments, reviews and decisions about what fairness should look like.

As programmes of reform continue across health, housing and social care, including the design and delivery of a National Care Service, the focus should extend beyond ensuring fair access to services, to ensuring that people can shape, sustain and trust the care they receive.

What happens next

SCIE will publish the full report in the coming weeks. It will provide more detail on the research findings, the experiences shared by participants and what the work adds to our understanding of care equity in adult social care.

In the meantime, SCIE invites local authorities, practitioners, policy colleagues, people drawing on care, unpaid carers and researchers to explore the **Care Equity Evidence Hub** and reflect on how equity can be embedded in local adult social care work.

Work with us on care equity

SCIE is supporting local authorities and partners to strengthen their understanding of care equity, use evidence more effectively and develop practical approaches to fairer adult social care.

For anyone interested in learning more about SCIE's care equity work, the **Care Equity Evidence Hub**, or related support offers, contact us at insights@scie.org.uk.



social care
institute for excellence

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.

Contact insights@scie.org.uk

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