About SCIE

The Social Care Institute for Excellence (SCIE) is an independent social care charity, collaborating and innovating with a wide range of partners and people with lived experience, to improve people's lives. 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, delivered through our four offers: innovative consultancy, expert training, extensive resources and information, and evidence-based insights.

Co-production with people with lived experience 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.

Need to talk? If today's discussion raises sensitive issues or you would like to speak to someone, please contact us at info@scie.org.uk.

Co-production:

The key to achieving care equity

Monday 29th June 2026

Sector concerns about inequity
Growing concern across policy, practice and lived experience highlighted persistent inequities in access, experience and outcomes in care.

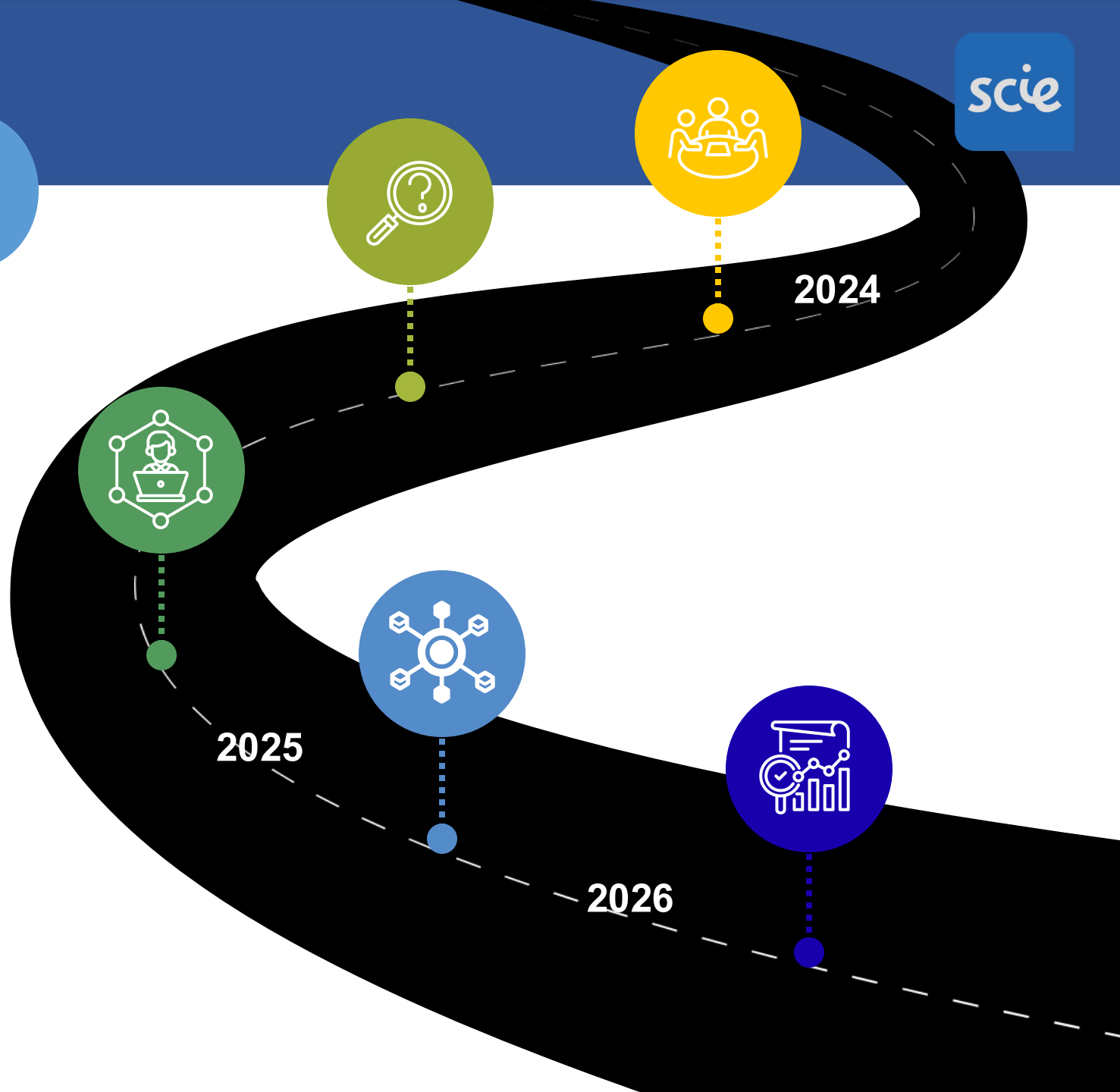
01 **Roundtables with the sector**
Structured roundtables brought together sector leaders, practitioners and people with lived experience to identify priorities and gaps.

02 **Establishing a shared understanding of equity**
Partners agreed a shared definition of care equity to create clarity and alignment across the system. A practical framework was also developed

03 **Evidence Hub (phase 1)**
Existing research and data was identified, appraised and mapped to the framework to build a structured evidence base and hub prototype

04 **Evidence Hub (Phase 2)**
Content was expanded, quality strengthened and navigation refined in response to user feedback. SCIE build of Evidence Hub undertaken

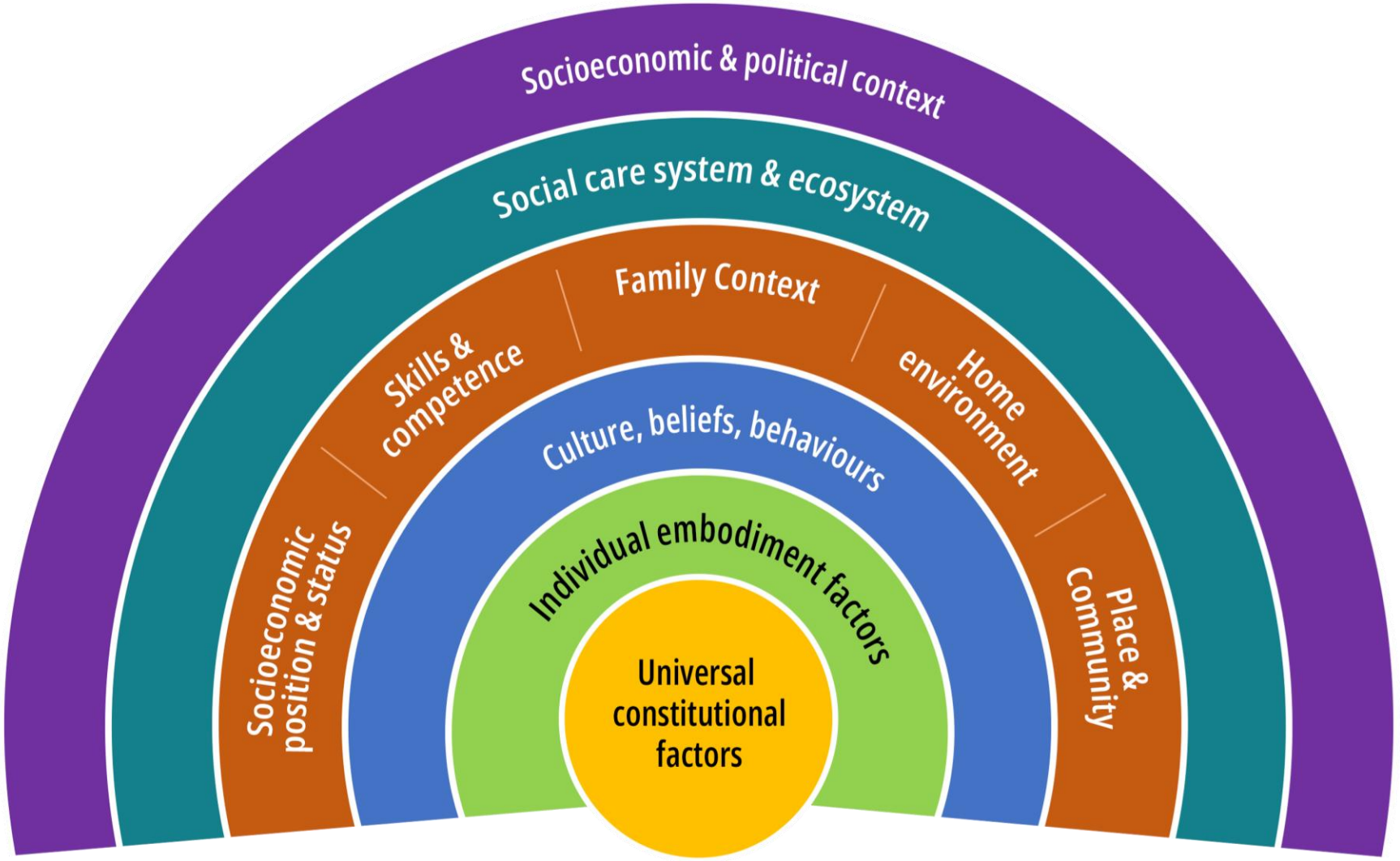
05 **Qualitative research commissioned**
Independent qualitative research has been commissioned by SCIE to deepen understanding of care inequities and explore lived experiences.



Establishing a shared understanding of care equity

Developing a framework

- A practical framework (Dimensions of Inequity Rainbow') was developed to describe the dimensions of systematic inequities in social care.
- It sets out how individual, community, system and wider socioeconomic factors interact.
- This provides a shared structure for analysing evidence and informing action.



Definition of Care Equity

Dr. Matthew Ford
Senior Research Analyst

"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."

Our co-produced definition of care equity:
Equity in social care means everyone should have a fair chance to get the care and support they need. No one should receive worse care, or miss out on care, because of who they are, where they live, or their circumstances.

Evidence Hub - Demo

Feedback from our stakeholders

It's a starting point to bring together evidence in social care

Professional

We need evidence to make social care more equitable.

Person with lived experience

"Gaps in evidence…people who don't want to engage with social care often get left out of research and out of reach to be included in evidence. This could be due to stigma, or barriers in the way of accessing social care."

Unpaid Carer

Having a central place to access up-to-date research would be invaluable. The more evidence, successes, challenges, and everything in between is shared openly rather than hidden away, the better it will inform our work.

Professional

Breakout room discussion

In your breakout rooms, please discuss:

1. What does care equity mean to you?

2. How do we achieve equity in social care together?

We are asking for one volunteer per breakout room to share a 1 minute summary of what was discussed.

Understanding People's Experiences of Inequities in Social Care: Qualitative research

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Our objectives

SCIE commissioned Thinks Insight & Strategy to conduct exploratory qualitative research to answer five key questions:

1. How do 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?

2. In what ways do 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?

3. What informal strategies do people drawing on care and carers use to manage or navigate gaps in formal social care provision?

4. How do structural and systemic features of the adult social care system contribute to feelings of exclusion, disempowerment, or invisibility among people drawing on care?

5. How can insights about people's lived experience inform the development of more equitable and person-centred adult social care policies and practices?

Overview of 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:

- **Immersion & design**

Mar-26

A rapid immersion phase combining a review of existing literature, expert stakeholder interviews, and collaborative refinement of stage 1 fieldwork through co-production.

- **Phase 1: Understanding experiences**

Apr-26

Exploring personal experiences of the care system via one of three modes of participation (online, paper and telephone).

- **Phase 2: Deepening insight and co-creation**

May-26

Deepening insight and exploring potential policy interventions through focus groups and depths with participants.

- **Phase 3: Continued engagement**

Jun-26

Development of a participant-facing summary report, alongside opportunities for continued involvement through follow-up engagement and an optional co-design workshop with participants and SCIE staff.

Recruitment was designed to capture variation in place, spending power and lived experience

Based on an initial **review of existing literature and data on recent changes in council funding,** we selected the following locations to ensure a diverse and representative sample:

North Tyneside council (11 participants): Coastal location, mix of urban and rural, adult social care spending power risen sharply.

Dudley Metropolitan Borough Council*(10 participants): : Post-industrial urban location, with a recently cut social care budget.

Westminster Council (14 participants): : Urban location, spending power fallen sharply.

Wiltshire Council (14 participants): : Rural location, spending power recently fallen.

We spoke to a total of **49 participants**.

Across the four locations, the sample included variation by:

- **Gender and age**
- **Ethnicity and migration background**
- **Socioeconomic circumstances**
- **Digital confidence**
- **Type and intensity of care**
- **Support needs, including mental health, physical disability, neurodivergence and cognitive impairment**
- **LGBTQ+ representation**

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Many see the social care system as opaque, with perceptions of scarcity shaping how they understand their needs

Many perceive the adult social care system as complex and opaque. Across the research, participants describe uncertainty about eligibility, funding, and provision.

Wider narratives of overstretched services shape perceptions and expectations of adult social care

For many, underfunded services serve as an explanation for experiences of poor care and leave many resigned to inadequate formal care. However, it also leads to a sense of guilt, for being a "burden" on the system.

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

Perceived scarcity shapes how people understand their own needs, entitlement to support and sense of deservingness

Many compare themselves with others they see more in need or make more complex judgements about who is or is not "deserving" of care, including concern that some people may be taking advantage of the system.

"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

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Good care is strongly associated with being listened to, 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 can reduce the burden of repeatedly explaining needs.
- **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.

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 conflicting emotions, for many, gratefulness and affection mix with guilt or even resentment.

"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

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

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Inequity is multi-dimensional and intersectional, it most strongly emerges when conditions overlap, interact and compound

Participants recognise inequities, but most commonly understand them through the idea of a "postcode lottery".

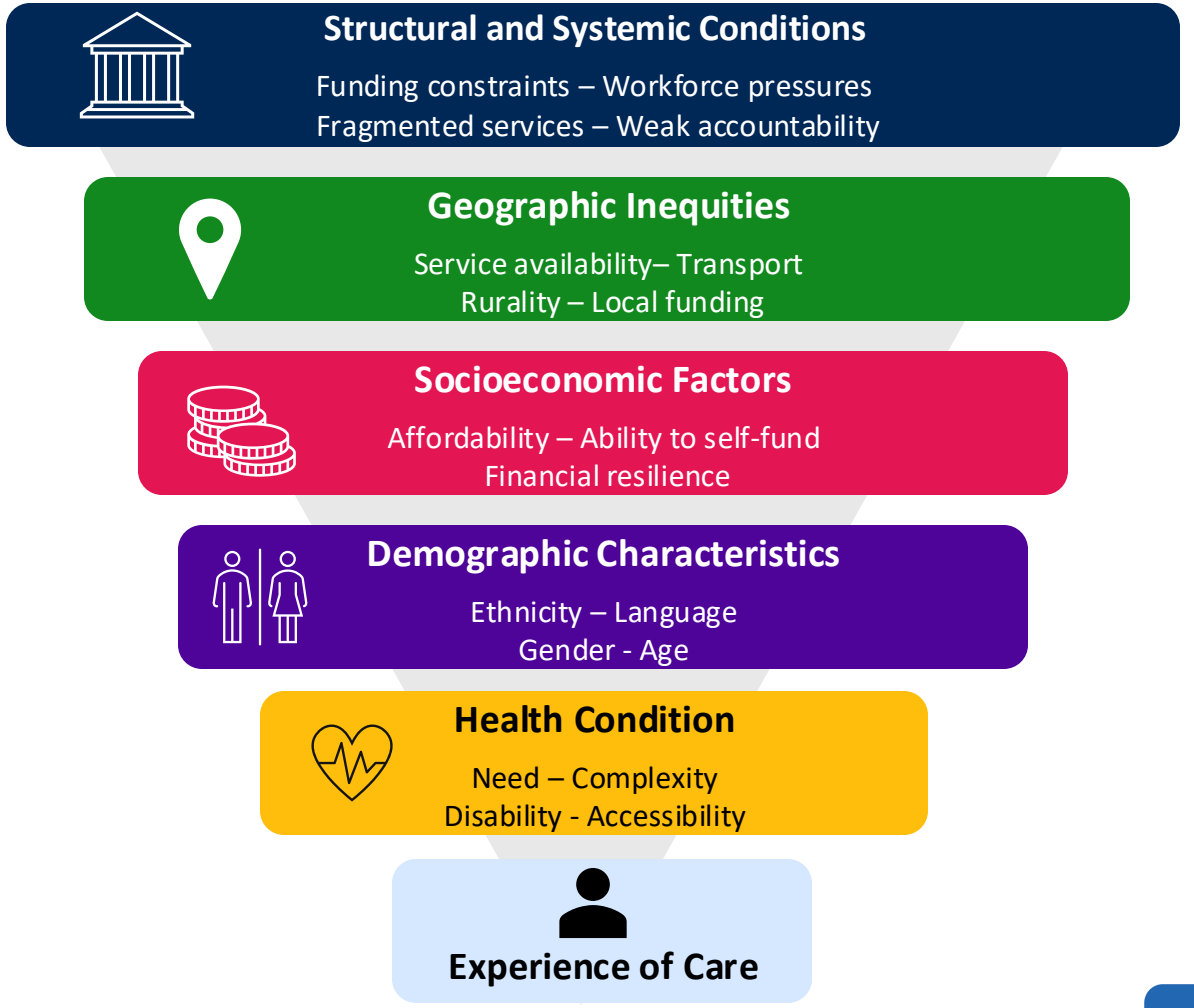
These geographical differences are recognised as unfair but are often accepted as an inevitable consequence of local funding pressures and service shortages.

"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 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



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Financial means, demographic factors and health conditions strongly affect access to and experiences of formal care

Some participants are satisfied with the amount and type of care they receive, particularly where they can pay privately. Others struggle to access more or better formal care because of cost, long waits, or the complexity of advocating for themselves

Demographic and health-related inequities affect access to care and the quality of people's experiences.

- **Participants from ethnic minority backgrounds** describe language barriers, unmet cultural and religious needs.
- **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 or invisible conditions** often face disbelief, and services that are not designed around how their conditions.

"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 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

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

Participants support six ideas that could better support people's care needs:

- **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**

"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

"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."

- 18-45, Male, City of Westminster

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Please share your feedback with us

Please scan the QR code below or click on the feedback link in the chat

Find out more at www.scie.org.uk or connect with us on LinkedIn.

If you are a local authority and are interested in care equity email us at info@scie.org.uk.

If today's session brings up sensitive issues, or if you would like to talk to someone afterwards, please contact info@scie.org.uk.