

ARTICLE

Reframing long-term care policy: from services to social determinants

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(Received 1 August 2024; revised 10 July 2025; accepted 23 September 2025)

Abstract

The organisation and financing of services dominate long-term care policy and research. This article argues for reorientation towards the social determinants of long-term care and the inequalities they generate. Building on Dahlgren and Whitehead's influential equivalent for health, the article offers a framework for understanding how inequalities in long-term care need, access and experience are shaped by social networks, living and working conditions, services and policies, social norms, and political, economic and environmental conditions. International evidence on inequalities in need, access and experience is reviewed, and new analysis is presented for England, based on analysis of the Health Survey for England and the Adult Social Care Survey. Socio-economic inequalities are associated with steep gradients in need. Combined with unequal access to formal services, this results in more unmet need among disadvantaged people and a greater weight of responsibility on their family and friends. The final section explores the implications of a social determinants' perspective for long-term care: addressing 'upstream' drivers of need (including social protection, housing and neighbourhood regeneration); inclusion and empowerment agendas; and ensuring that services effectively compensate for, rather than re-enforce, inequalities.

Keywords: social determinants; inequality; disadvantage; long-term care; disability; unmet need

Introduction

What is the 'problem' of long-term care? Why is it perennially in 'crisis'? Typical responses include that societies are facing increased demand for services due to population ageing and that funding for long-term care is inadequate. There is truth in both these assertions. But in this article, I will argue that framing long-term care policy around ageing, services and financing obscures another important explanation, which is that the problem of long-term care is substantially a problem of inequalities, rooted in social and economic determinants, which generate need, impair access to support and contribute to a poor experience of care.

In health policy and research, recognition of inequality and the associated concept of the social determinants of health has become mainstream (WHO, 2024; Marmot, 2020). But when it comes to long-term care research and policy, that perspective seems to lose focus. Needs for day-to-day support are seen as necessary corollaries of age, overlooking the strong social gradients in the incidence of need and in the conditions in which people navigate their lives.

The contribution of the article is primarily conceptual: making the case for the value of a social determinants perspective on how long-term care needs arise, what affects access to support and how support is experienced, and exploring the implications of reframing long-term care policy in this way. The relevance of this approach is illustrated with some evidence on inequalities in care need, access and experience in England. England provides a stark example because of its high levels of underlying economic inequalities (Gornick, 2024) and relatively low coverage of publicly funded long-term care compared with, for example, the Nordic countries, France, Belgium or the Netherlands (Llena-Nozal et al., 2025).

The structure is as follows: In the next section, I describe the tendency in policy debates to frame long-term care around demographic change, services and financing, and contrast this with alternative frames offered by active ageing and care poverty. I set out how the social determinants approach could be adapted and applied to long-term care, and discuss how this reframing draws attention to the potential for inequalities in care to arise. The following section illustrates some of these inequalities, examining economic and ethnic inequalities in need, access to care and the experience of care in turn. It draws on existing international evidence and adds new analysis for England, using data from the Health Survey for England and the Adult Social Care Survey.

The final section argues that the scale and pervasive nature of the inequalities observed, both in England and elsewhere, lend weight to the argument for shifting long-term care research and policy from a focus on services and provision of care to incorporate a broader social determinants perspective. The implications for research and policy of starting from an analysis of what creates need and impairs access, rather than from the organisation and financing of services, are drawn out.

To clarify some terminology: long-term care provision refers to support in people's own homes or in residential settings, for adults who need help with day-to-day activities, including getting around, socialising, managing money, or eating and washing. Needs arise from an interaction between the context in which someone lives and lifelong conditions (such as complex learning disability), chronic conditions including depression and dementia, or injuries. Younger adults may be referred to as 'disabled people' (in UK English), whereas people aged 65 or over are typically referred to as 'older people', although the distinction by age is arbitrary (Torres-Gil and Ambriz, 2024).

Care is a contested term. When 'care' is understood relationally and affectively, receiving, and giving, care is seen as intrinsic to being human (Daly 2021; Dean, 2023). Only when viewed through the lens of service provision does 'care' betoken assistance with particular types of activities. Social Care Future, a movement of people with direct experience, use the phrase, 'people who draw on support' (2024), emphasising both the agency of the person *drawing on* support and the continuum

between people who draw on additional support and those who can generally get by with less.

Formal care refers to services provided by organisations, whether funded publicly (through taxation or social insurance) or privately (by individuals and their families). Support provided by family and friends, which makes up the lion's share of all support, is referred to as 'informal', 'unpaid' or 'family' care. Although none of these labels is entirely satisfactory, I use 'unpaid' below.¹

Framing and re-framing long-term care

'Framing' in public policy includes, among other things, the processes of naming, selecting, categorising and narrating the policy problem and its solution (van Hulst and Yanow, 2014). One prominent framing of long-term care policy is that, owing to the combination of an ageing population and the waning supply of unpaid care, countries are facing challenges in financing and providing care services. Examples of this can be found in policy documents produced by international organisations (for example, WHO, 2017; Asian Development Bank, 2022), national governments (for example, terms of reference for the independent commission in England, DHSC, 2025; the final report of Australia's Royal Commission on aged care, 2021) and non-governmental organisations (for example, the International Federation on Ageing, n.d.).

This framing embeds within it a number of assumptions. Naming 'long-term care' as a policy area already suggests a service lens – the provision of something over a period of time – as distinct, for example, from starting from a person with agency, whose needs change over time, or from a relationship, or from a set of material conditions. Selecting older people as the focus, through the emphasis on the 'ageing population', suggests that age itself (rather than impairment and living conditions) denotes a higher need for care, and sidelines the needs of working-age disabled people. The categories of long-term care recognised in policy documents adopting this framing tend to position family care as the default, turning to privately and publicly funded services when unpaid care is unavailable. Together these elements are woven into a narrative that defines the policy problem as the mismatch between increased need (due to ageing) and reduced supply of unpaid care (due to changes in family structure and increased female labour market participation), leading to pressure on public services. The varied policy solutions proposed often include expanding and upskilling the long-term care workforce while reforming services to keep costs down.

The 'services-financing' frame is also reflected in long-term care research. Daly's (2021) review of the last four decades of research on 'care' identifies as two core themes the organisation of services in the welfare state, and the financing and effectiveness of interventions. Another of Daly's themes adopts a different frame, selecting carers rather than older people as the focus and categorising care as a form of labour – whether paid or unpaid – and leading to more critical narratives about the distortions of relationships under patriarchy and capitalism.

Centring the people who draw on support shifts the frame again. In research, this has led to naming and categorising needs (rather than services), and specifically to

narratives of unmet need, where neither formal nor unpaid care are adequate (for example, Vlachantoni et al., 2024). The ‘needs’ frame has been extended by the ‘care poverty’ approach (Kröger, 2022), which treats formal and unpaid care as resources that are distributed according to institutions, policies and cultural norms and begins to open up a narrative about the importance of the broader social and economic context. The broader context also features prominently in the healthy ageing policy framing of the World Health Organization (WHO, 2015), which articulates an ambition to maximise older people’s capabilities, recognising that these depend not only on their ‘intrinsic capacity’ but also on institutional and environmental factors.

Social determinants

The care poverty and healthy ageing frames both point towards the potential usefulness of a social determinants framework. Crucially, the social determinants of health (SDOH) framework can bring into the narrative the process by which needs are created, not just how they are met (or not) once they have materialised. Since its inception in the early 1990s, this framework has become ubiquitous in health policy research and has been instrumental in advancing health inequalities up the policy agenda (Dahlgren and Whitehead, 2021). The central tenet is that health outcomes are driven substantially by people’s social and economic conditions, with the implication that health policy must extend well beyond healthcare (Woolf, 2019). The observation that living and working conditions give rise to pervasive health inequalities was highlighted as early as 1980 in the Black Report (DHSS, 1980), which was influential in the Organisation for Economic Co-operation and Development (OECD) and WHO, and subsequently led to the Marmot Review (2010) in the UK. Later work emphasised the accumulation of health disadvantage due to living and working conditions across the lifecourse (Marmot, 2020). Economic inequalities interact with other forms of social stratification and discrimination, especially in relation to ethnicity; therefore health inequalities need to be understood intersectionally (Bambra, 2022). Moreover, the effects of social determinants are observed not only in the risks of developing health conditions, but also in the ease and timeliness of access to both preventative healthcare and treatment, and in patient experience and outcomes (Diderichsen et al., 2001).

Some of the conditions – dementia, for example – found to have strong social gradients in the health inequalities literature (Bodryzlova et al., 2023) are also central drivers of long-term care needs, and yet the care literature has a tendency to see ‘older people’ or ‘disabled people’ and implicitly erase any socio-economic circumstances that may have contributed to the person becoming as they are. Vlachantoni et al. (2015) is an exception in acknowledging the relevance of socio-economic characteristics on the creation of need and on access to different forms of support; Zarkou and Brunner (2023) also connect the socio-economic gradient in health conditions and impairments with levels of need for care and unmet need.

One explanation for the lack of take up of SDOH in research on care may be that the hard-won victory of the disabled people’s movement to overturn the medical model of disability has left a legacy of suspicion of concepts that originate in health research, and a reluctance to discuss conditions and impairments, in favour of a social model of disability (Oliver, 1996). The concern seems misdirected in this

instance, however, since SDOH, like the social model, identifies disadvantage as arising from an interaction between a person's characteristics and their environment, and both approaches seek to de-centre healthcare as a policy response.

Another part of the explanation may be that, compared with care, recognition of 'the highest attainable standard of health' as a human right came earlier and was more widespread. Recognition implies also a commitment to tackling inequalities in health, including through providing universal access to healthcare. This is reflected in many countries' institutional arrangements, with healthcare free or nearly free at the point of use, at least in principle, and the health of the population subject to multiple national government policies, strategies and plans. By contrast, long-term care is often means-tested, localised and under-resourced. This fragmentation and residualisation has perhaps made it harder to notice the patterns in who develops a need for care and to identify the social and economic determinants.

Making the social determinants of care more explicit brings into focus upstream inequalities in living and working conditions that contribute to the development of care needs in the first place, as well as shaping access to, and the experience of, support. It invites us to consider how inequalities may accumulate over the lifecourse. It sensitises us to the possibility of intersectional disadvantages, discrimination and marginalisation of minorities. Connecting long-term care research to the SDOH framework has the potential to expand the policy debate beyond its preoccupations with demographics and financing, towards a richer terrain encompassing multiple aspects of social and economic arrangements and invites the question of what it would mean for long-term care *policy* to be about more than long-term care services.

Figure 1, building on Dahlgren and Whitehead's (1991) rainbow diagram of SDOH, offers a schematic representation of a proposed re-framing of long-term care policy, based on the social determinants of long-term care needs, access and experience. It shows three inter-related 'rainbows'. The largest, labelled 'Needs', shows a person with needs (and their carer), surrounded by arcs indicating layers of influence on their needs. In the red centre are the person's own characteristics (for example, ethnicity). The next arc (yellow) consists of social and support networks, followed by living and working conditions, and institutions, policies and services (green) and finally social and cultural norms and the general economic, political and environmental conditions (blue). The characteristics in the arcs are understood to interact, such that, for example, the effect that ethnicity has on the generation of care need is mediated by the extent to which discrimination is a social and cultural norm.

Access to formal care features under institutions, policies and services in the green arc of the 'Needs' rainbow, and access to unpaid care features in social and support networks in yellow, because timely access to the right kind of support can pre-empt or reduce needs, and, conversely, inadequate access to support can lead to more rapid progression of needs. But access to both formal and unpaid care are themselves subject to social determinants. For this reason, a second rainbow, labelled 'Access', is shown as feeding into 'Needs'. The social determinants of 'Access' are arranged in similar layers to the determinants of 'Needs', but their content is different, as illustrated in Table 1. Finally, access to formal or unpaid care is influenced by a person's experience of care in the past and with other services and

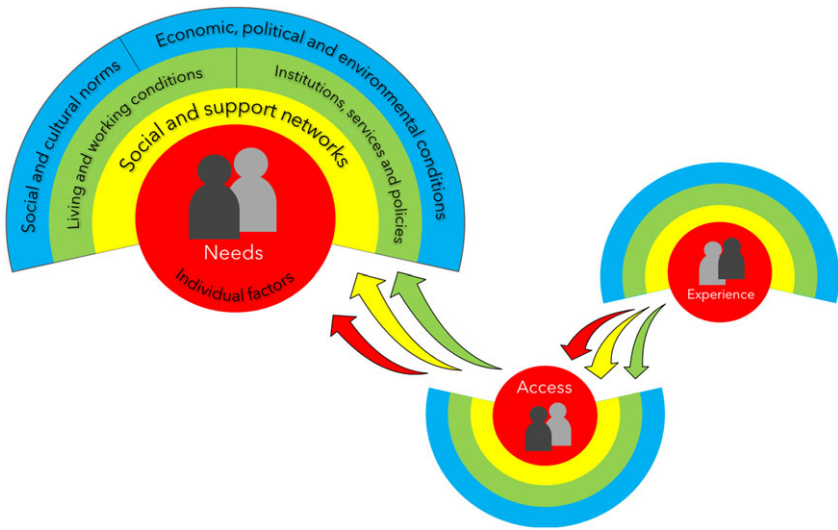


Figure 1. Framework for social determinants of long-term care needs, access and experience.

Source: Author's graphic, adapting Dahlgren and Whitehead (1991) social determinants of health model and using graphics template provided by RianHS Determinants of health model ID.svg under CC-BY-SA-4.0 license.

family members, and experience itself is subject to social determinants, as represented by the third rainbow.²

The content of each arc of the three rainbows suggested in Table 1 below the figure is speculative and incomplete but serves to illustrate some phenomena for which there is already evidence and some where more investigation is needed. For example, under 'Needs', poor housing conditions (included in the green arc) are known to be a key predictor of the early development of care needs among older people in China and in England (Li et al., 2023 and Cartagena Farias et al., 2023). We also know that age (in red) is an important determinant, but how this interacts with educational attainment, income and neighbourhood conditions (in green) is less well understood; some explorations are offered in the next section.

The concept of care poverty (Kröger, 2022) is reflected in the 'Access' rainbow, including, for example, how different care norms and long-term care regimes (in blue), in combination with lack of support for carers (in green), can result in gaps in care, particularly for those in low income households and areas (also in green) – investigated in the sub-section on access to care below. Specifically for people with dementia, a systematic review of the barriers to accessing long-term care (Giebel et al., 2024) identified five themes which are reflected in Table 1. Psychological barriers including confidence and care preferences are included under 'Individual factors' in red. Situational barriers identified by Giebel et al., for example low income and lack of services appropriate for the person's impairment, are included under 'Living and working conditions' and 'Institutions, services and policies', respectively. Interpersonal barriers refer to relationships between people with dementia and paid and unpaid carers. These are a thread running through all the categories in the 'Access' column in Table 1: from care norms in blue, through

Table 1. Illustrative social determinants of needs, access and experience

Arc	Needs	Access	Experience
<i>Social and cultural norms Economic political and environmental conditions</i>	Role expectations; discrimination; physical environment; social and economic development	Care norms; discrimination; long-term care and welfare regime; public finances and political priorities; demography	Care norms; discrimination
<i>Living and working conditions Institutions, services and policies</i>	Maternity and child development; education; occupational health and safety; earnings and social security; healthcare; housing; social inclusion and active ageing policies; neighbourhood conditions	Transport; neighbourhood; housing; income; social security; healthcare; long-term care workforce; long-term care funding and eligibility; support for carers; social inclusion and active ageing policies	Support for carers; care workers' terms and conditions; social inclusion and active ageing policies; effectiveness of other services, e.g. housing, social security, employment, neighbourhood
<i>Social and support networks</i>	Support from family and friends; wider support network; advice and advocacy	Capacity, proximity and willingness of family and friends; wider support network; advice and advocacy	Quality of relationships; wider support network; advice and advocacy
<i>Individual factors</i>	Age, sex, ethnicity, genetic inheritance, take-up of preventative measures; lifestyle	Age, sex, ethnicity, nature of impairment, literacy; confidence; care preferences	Age, sex, ethnicity, nature of impairment, choice and control

support for carers in green, advice and advocacy in yellow, to care preferences in red. Structural barriers in Giebel et al.'s terminology include lack of information, unsuitable services and geographically inaccessible services; these are central to the 'Living and working conditions' and 'Institutions, services and policies' categories shown in green.

The final theme in Giebel et al.'s review is cultural barriers, including language barriers, stigma and insensitive care. This theme points to the 'Experience of care', which is treated as a separate column in Table 1. Giebel et al. highlight the particular risks for migrants, religious and ethnic minorities; inequalities in the experience of care for different ethnic groups in England are examined in the 'Experience' subsection below. The effects of the choice and control that someone has over their care (in red) and the conditions of the care workforce (in green) on the relationships they are able to build, and hence the experience of care, have been examined in other studies (Lewis and West, 2014).

Inequalities in need, access and experience

The nature of many of the potential social determinants of care leads us to expect that people with lower socio-economic status will have higher needs. In addition,

many potential social determinants interact with ethnicity. To assess the empirical relevance of the social determinants of care approach, some of the international evidence on socio-economic and ethnic inequalities in long-term care need, access and experience is reviewed in the next three sub-sections, respectively, and some new evidence for England is presented.

The analysis for England draws on two main sources: Health Survey for England (HSE), which permits analysis of older people's needs and access to care, and the Adult Social Care Survey (ASCS), which offers insights into the experiences of both working-age and older people drawing on support funded or managed by local authorities. HSE is a cross-sectional survey aiming to be representative of the household population, with an individual response rate of 55% in 2019.³ Individual-level weights supplied by the data owners to minimise the effects of sample design and non-response bias were applied. It was necessary to pool three years of data to obtain a sample size sufficient for this analysis: 5010 respondents aged 65 or over with non-missing household income and ethnicity information. The years 2017–2019 were selected as the most recent available not to have been affected by the pandemic. Needs for support are indicated by the number of activities of daily living (ADL) and instrumental activities of daily living (IADL), with which respondents need help; regrettably these questions are asked only of respondents aged 65 or over.⁴

ASCS is a survey of adults drawing on support funded or managed by local authorities. The sampling frame is provided by administrative data and is stratified by a combination of age group (18–64, 65+), care setting (residential or community) and whether the primary reason for support is learning disability. A minimum sample size is specified for each local authority. In 2021–22, the year used for this analysis, the total achieved sample was 59,770, a response rate of 27%. Although low compared with general population surveys, this is to be expected for a sample who by definition face additional challenges.⁵

Need for care

Categories of impairment that commonly give rise to needs for support include, for people of working age, learning impairments, musculo-skeletal and neurological conditions, and severe mental illness. To what extent are these socially determined? A gradient in the prevalence of impairments with respect to socio-economic status is consistent with the social determinants hypothesis, but also with causation running in the opposite direction, from impairment to low earnings. Focussing on lifelong conditions that are diagnosed at birth or in childhood helps to reduce the ambiguity. The evidence is mixed. For example, Down's syndrome, spina bifida and autism do not exhibit any marked social gradients, whereas non-specific developmental disorders and learning impairments are associated with greater exposure to toxins and illness during pregnancy, complications during birth and severe childhood illness and injury (Solaski et al., 2014), all of which are more common among families with lower socioeconomic status. Low birthweight, which is more common among babies born into families in poverty, is a significant risk factor for cerebral palsy (Krewski et al., 2017).

Widening the scope to conditions that may arise in adulthood, socio-economic disadvantage is a risk factor for traumatic brain injury (for example, as a result of traffic accidents or assaults) and multiple sclerosis (Krewski et al., 2017; Solaski et al., 2014). There is no evidence for a social gradient in bipolar disorder (Grande et al., 2016), but there is for anxiety and depression (Allen et al., 2014) and for schizophrenia, for which adverse childhood experiences, homelessness, growing up in a poor neighbourhood and experiences of discrimination (especially for people from minoritised ethnic groups) are risk factors (Jester et al., 2023).

For older people, dementia, arthritis, stroke, diabetes, cardiovascular disease, respiratory conditions and falls are major contributors to long-term care need, and all of these have a pronounced social gradient, reflecting the accumulation of health disadvantage over the lifecourse (Marmot et al., 2020). The risk of developing dementia is robustly associated with prior socio-economic disadvantage (Adkins-Jackson, 2023; Bodryzlova et al., 2023). The development of arthritis, including the most severe kinds, is associated with occupational exposure during working life: people frequently engaged in repetitive heavy manual work have nearly double the risk (Unverzagt et al., 2022). Stroke shows consistent independent association with individual-level deprivation, and cardiovascular disease with both individual and neighbourhood-level deprivation and ethnicity (Teshale et al., 2023). Low income is a significant risk factor for developing type 2 diabetes (Hill-Briggs et al., 2021), as is ethnic minority status (Pham et al., 2019). Older people with lower socio-economic status have more falls (Liu and Hu, 2022; Pitcahi et al., 2019; Ryu et al., 2017), and there is also an association with neighbourhood disadvantage (Lo et al., 2016).

For both working-age and older people, then, many of the main impairment types that give rise to needs for support with day-to-day living are more common among ethnic minorities and exhibit socio-economic gradients. Moreover, the environments in which people live tend to compound rather than offset the disadvantage, meaning that the same impairment is more disabling. For example, someone with a mobility impairment living in a high-rise block served by an unreliable bus service is more likely to need support for getting to appointments, shopping or meeting friends, than someone with the same condition who lives in a well-adapted bungalow and has access to a car.

Turning to the case study of England, ethnic differences and socio-economic gradients in needs for support among older people can be examined using HSE data. As expected, the number of ADLs and IADLs with which people need help rises steeply with age. But Figure 2 shows that, at the age of 65–69, people in the lowest fifth of the income distribution already have, on average, nearly three times as many ADLs or IADLs with which they need help as those in the top fifth of the income distribution. Indeed, the latter do not develop that level of need until they are around age 85, on average. Differences between ethnic groups, controlling for age group, are also significant: Black people aged 65 or over report 0.83 more ADLs and IADLs with which they need help than White people, and Asian people 0.90 more, controlling for age.⁶

Local area deprivation is an independent social determinant of need among the older population. Dividing neighbourhoods in England into fifths according to their Index of Multiple Deprivation (IMD) score, over-65s living in the most deprived neighbourhoods report, on average, 1.3 more ADLs/IADLs with which they need

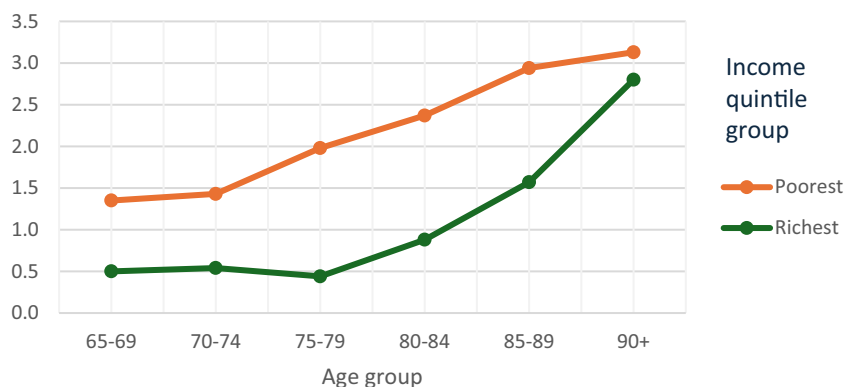


Figure 2. Average number of ADLs/IADLs with which help is needed, by income and age group, England 2017–2019.

Source: Author's analysis using Health Survey for England pooled data for 2017, 2018 and 2019.

Notes: ADLs are nine activities of daily living; IADLs are four instrumental activities of daily living (see endnote 4 for full list). Unweighted sample size 5010. Individual-level weights applied. Income quintile groups are defined using the whole-population equivalised household disposable income distribution.

help than their counterparts living in the least deprived neighbourhoods, even after controlling for household income, age and ethnicity.⁷ In fact, area deprivation has a stronger association with need for those on lower incomes than it does for those on higher incomes (Figure 3), suggesting, perhaps, that it is possible to compensate for poor facilities and infrastructure to some extent through private means – such as a car.

For people of working age, Banks et al. (2023) use highest educational qualification as an alternative indicator of socio-economic status (qualifications being acquired mainly before prime working age) and show that people in their early thirties (30–34) in the UK with no formal qualifications have nearly *four times* higher rates of limiting long-standing disability than people with degrees (27% compared with 7%). Prevalence of disability generally rises with age, but the proportion of people with no educational qualifications who are living with disability in their early thirties already exceeds the proportion of people with a degree who are living with disability in their late sixties (23% among 65–69s) (Banks et al., 2023)⁸.

Some reverse causation is a possibility (impairments acquired before age 30 could have limited the education the person was able to access), but the strength of the association is such that that is unlikely to be the only explanation. The social determinants interpretation is lent further support by older evidence which showed that, in the 1990s, working-age (16–59/64) people with no educational qualifications were more than three times as likely to *develop* a work-limiting disability in a given year than people with a degree (Jenkins and Rigg, 2004, table 2); and also by evidence from a British birth cohort study, which showed that childhood socio-economic disadvantage was associated with more than a 50 per cent increase in the likelihood of developing a limiting long-standing illness by the age of 33 (Power

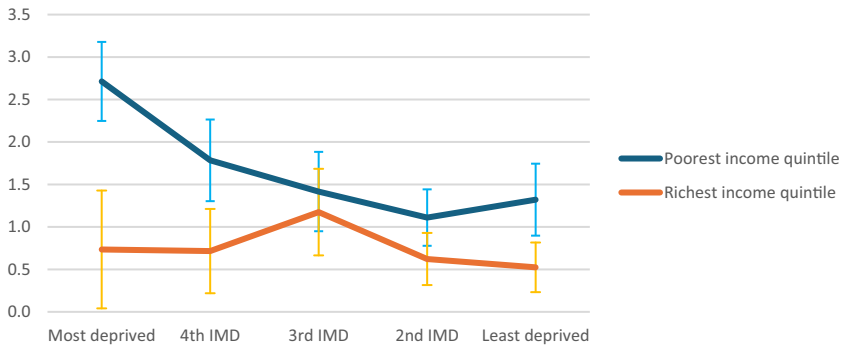


Figure 3. Predicted number of ADL/IADLs with which help is needed, by household income group and area deprivation, England, 2017–2019.

Source: Author's analysis using Health Survey for England pooled data for 2017, 2018 and 2019.

Notes: Ordinary least-squares (OLS) regression of number of ADLs/IADLs with which help is needed on income quintile group *interacted* with IMD quintile group, with additional controls for age groups and ethnic groups. Error bars show 95% confidence intervals. Estimation sample 4999; aged 65 or over only.

et al., 2000, table 6). By no means everyone with a limiting long-standing illness or disability needs support with day-to-day living, but a subgroup does, and both the cross-sectional and longitudinal evidence suggests that there is a strong socio-economic gradient in the overall risk.

Access to care

Higher need among socio-economically disadvantaged groups could in theory be addressed through greater access to support. Privately-paid-for services cannot close the gap, since only those with the necessary financial means can access them. Three aspects of publicly funded long-term care determine the extent to which it is effective in this respect: eligibility criteria relating to income and wealth; eligibility criteria relating to the types and levels of need and services; and levels and sources of revenue. These operate jointly; addressing the higher needs of socio-economically disadvantaged groups requires universal entitlements or a means-test set sufficiently high that those excluded can afford to self-pay *and* inclusive needs tests to ensure that the services provided are comprehensive *and* a sufficiently high level, and equitable distribution, of public funding to avoid de facto rationing.

These are stringent requirements, and it is not surprising to discover that socio-economic inequalities persist in who receives help and whether their needs are met. For example, in Spain, Garcia-Gomez et al. (2015) report a strong pro-rich distribution of access to formal care, and that unmet needs for care are concentrated among low-income families. Across Southern Europe, lower socio-economic status is associated with higher chances of unmet need (Albuquerque, 2022). Low-income families are also more likely to be affected by geographical barriers to accessing care, as found by Kyriopoulos et al. (2014) for Greece (cited in Giebel et al., 2024). By contrast, for Finland, with its predominantly universal and comparatively generous

long-term care system, Kröger et al. (2019) found no relationship between unmet needs for personal care and household income, although they did find higher levels of unmet need for support with instrumental activities of daily living among poor households. This underlines the relevance of the eligibility criteria relating to needs, not just means.

In the English context, stringent means-testing, needs tests that exclude all but the highest levels of need, and reliance on local revenue are prominent features (Bottery and Curry, 2025); when combined with chronic under-funding for long-term care as a whole (Burchardt et al., 2020), substantial levels of unmet need are inevitable. Recognition that the system is in need of reform is widespread, but as Needham and Hall (2023) document, England has suffered from prolonged ‘policy drift’ at a national level, failing to make personal care free at the point of use (unlike Scotland) and repeatedly shelving the planned lifetime cap on care charges. Meanwhile, local authorities have struggled to take advantage of the duties given to them in the Care Act 2014 to ‘shape’ the care market in their area, because of the tensions between user choice and control, partnership working, and open competition, as well as tightly constrained budgets and considerable uncertainty over costs (Needham et al., 2023).

Multiple studies report that unmet need for care is concentrated among socio-economically disadvantaged groups in England (Burchardt et al., 2018; NHS Digital, 2019; Vlachantoni, 2019; Hu et al., 2024). Repeated unmet need among older people who need help with bathing or dressing was found by Vlachantoni et al. (2024) to be associated with increasing levels of need (as indicated by ADLs), living alone, being divorced or single, or changing living arrangements. Although older people in the lowest wealth quintile group were substantially more likely to have needs for help with bathing or dressing at the outset, Vlachantoni et al. did not detect any consistent relationship between wealth and *changes* in whether these needs were met over the 2-year observation window.

Unmet need is typically assessed in quantitative analysis by comparing stated needs for assistance with whether any support, formal or unpaid, is received. Unpaid care may be preferred to formal care – by the person with needs, by the carers, or both. However, providing unpaid care, particularly at higher intensities or when the carer has little discretion about whether to take on the role, can create significant strains on the carer and in the relationship with the person who needs support (Brimblecombe, 2023), so it is important also to look separately at the socio-economic gradients in the receipt of formal care and unpaid care.

Among working-age people with a high level of need, in England, Burchardt et al. (2018) found that, controlling for other characteristics, people in the each of the top three-fifths of the income distribution were respectively 11, 16 and 22 per cent more likely to be receiving formal care than those in the bottom two-fifths. The three higher-income groups were also more likely to be receiving unpaid care, but without a clear gradient between them.

For older people, new analysis of HSE data for 2017–2019 shows that, holding constant the level of need (as proxied by ADL/IADLs) and age group, someone in the lowest two income groups is much less likely to receive any formal care than someone in the highest income group.⁹ By contrast, the distribution of unpaid care is skewed significantly towards people in lower-income households. Table 2 shows

Table 2. Predicted probabilities (%) of receiving care among adults who need help with two ADLs/IADLs, by income group and age, England, 2017–19

Age group	Household income quintile group	Any formal services	Any unpaid care	Unpaid care of 10+ hours per week
65–69	Poorest	1.8	13.9	3.6
	Second	1.8	10.1	2.7
	Third	3.3	8.9	2.5
	Fourth	4.2	7.7	1.5
	Richest	3.5	5.0	0.1
80+	Poorest	9.0	30.0	5.8
	Second	9.0	23.8	4.4
	Third	14.1	21.7	4.1
	Fourth	16.7	19.4	2.6
	Richest	14.6	13.9	1.7

Source: Author's analysis using Health Survey for England pooled data for 2017, 2018 and 2019.

Notes: Probit regression of whether care received, on number of ADL/IADLs with which help is needed, age group, ethnicity, and equivalised household income quintile group. Table shows predicted probabilities based on the marginal effect of household income groups, evaluated at different ages and two ADL/IADLs. Estimation sample 5010; aged 65 or over only.

the predicted probability that a person aged 65–69, and a person aged 80 or over, who needs help with two ADL/IADLs will receive any formal services, or any unpaid care, across the household income distribution. Such a person towards the bottom of the income distribution is roughly half as likely to receive formal services as an otherwise similar person towards the top of the income distribution. In addition or instead of formal care, someone in the bottom income groups is much more likely to be relying on unpaid care: two and a half times more likely than someone in the top income group. The gradient is steeper still for higher intensities of unpaid care of 10 hours per week or more: at age 80 or over, those in the bottom fifth of the income distribution are more than three times as likely to be drawing on care of this kind compared with those in the top fifth of income distribution.

Unpaid care fills some of the gaps left by formal services in responding to the greater needs of the socio-economically disadvantaged. Needs that are met only through unreasonable or unsustainable burdens on carers should arguably not be considered 'met' at all, rather evaluated for the dyad – the person with needs and the main carer, or indeed the wider support network (Brimblecombe, 2023). Moreover receiving help does not necessarily mean that your needs are met: the support received may be too infrequent, at the wrong times, partial, mis-directed, inappropriate or unwelcome. The next sub-section turns to inequalities in the experience of receiving care.

Experience of care

In addition to barriers to accessing services, there may be inequalities in users' experience of services. This is particularly apparent in relation to ethnic inequalities. In the USA, Travers et al. (2020) found that African-American older adults expressed less participation in decisions about their care than their White counterparts; some even felt 'tricked'. In Denmark, dementia care workers did not always speak the same language as the people from ethnic minorities they were caring for, leading to a lack of cultural sensitivity (Nielsen et al., 2021 cited in Giebel et al., 2024). For England, Brimblecombe (2022) found that ethnic minority care dyads were less likely to receive services appropriate to their needs; language barriers, mis-matched expectations and the attitudes of professionals may contribute (Moriarty, 2008).

The ASCS allows us to investigate quantitatively the experience of people who draw on support funded or managed by local authorities in England. The large majority of respondents have low income and wealth, because eligible for means-tested publicly funded care. The sample is stratified by whether the person receives support primarily for learning disability and then, exclusive of that group, by age and support setting. Respondents are asked to select statements that correspond most closely to how they feel about themselves, and about being able to do what they value or enjoy with their time, having social contact, feeling safe, being in a clean and comfortable home, getting adequate and timely food and drink, and feeling clean and presentable.

As Figure 4 shows, a substantial minority of service users do not feel adequately supported in these respects. Overall, one-third of service users have insufficient opportunity to do things that they value or enjoy with their time, and 28 per cent are socially isolated or do not have enough social contact. The proportions are particularly high among working-age people (other than those supported mainly with learning disability) and among older people living in the community. Perhaps most troublingly of all, 11 per cent of service users overall report that the way they are helped or treated 'sometimes' or 'completely' undermines how they think or feel about themselves – 4 per cent of people supported with learning disability, 9 per cent of older people in residential care, 13 per cent of older people in the community and 16 per cent of working-age people (exclusive of those with learning disability).

Consistent associations between poor experience and ethnicity are apparent (Figure 5). In relation to each of the eight indicators, people who draw on support who identify as Black or Black British, or as Asian or Asian British, are more likely to report inadequate support. For example, 14 per cent of the former and 12 per cent of the latter say that how they are helped or treated sometimes or completely undermines how they think or feel about themselves, compared with 10 per cent of the White ethnic group.¹⁰ These discrepancies merit further investigation, including qualitatively, to understand the extent to which they reflect overt discrimination, lack of cultural sensitivity and/or interaction with the other aspects the circumstances and needs of ethnic minority people who draw on support. They underline the importance of including ethnicity as a characteristic and discrimination as one aspect of social and cultural norms in the analysis of the social determinants of care (Table 1).

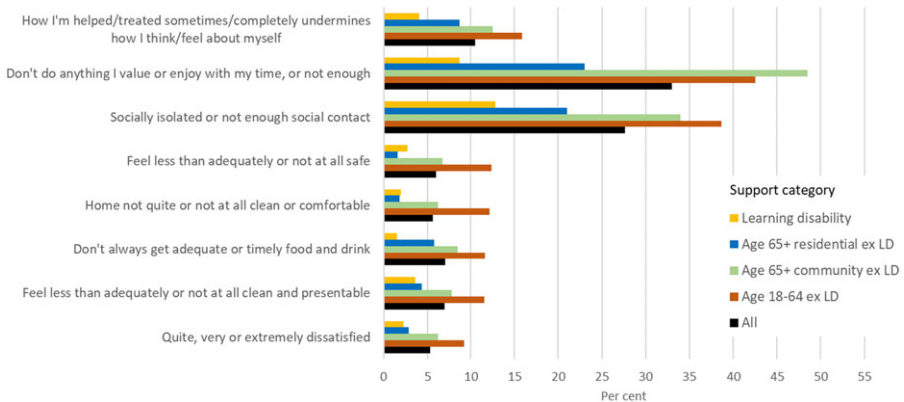


Figure 4. Service users' experience of public formal care, England, 2021–22.

Source: Author's analysis using Adult Social Care Survey, 2021–22.

Notes: (1) The sample is stratified by the categories shown in the legend, defined to be mutually exclusive. All clients receiving support primarily for learning disability are in the first category, regardless of their age or support setting. (2) Results are weighted to take account of sample design and differential non-response.

From services to social determinants

The empirical analysis presented in this paper inevitably suffers from some limitations. Firstly, the metrics of need and experience used in surveys cannot reflect the rich description of qualitative studies and are especially limited for working-age people. Secondly, finer-grained ethnicity classifications would facilitate greater insight into ethnic inequalities. Thirdly, and most significantly, the analysis presented is for only one country. England has high levels of social and economic inequalities compared with many other rich countries, combined with lower coverage of publicly funded long-term care than in Nordic welfare states and some other European countries. In these respects, it is an instructive but not a typical case. Although the brief reviews of international evidence also point to the existence of social gradients in need, the case the paper seeks to make for social and economic inequalities being central to understanding long-term care needs, access and experience would certainly be strengthened by dedicated empirical analysis for other countries. Understanding how effective different policy environments are in reducing the translation of inequalities in underlying need into inequalities in access and experience could be another interesting area for research.

Social and economic inequalities in care indicate the potential relevance of a social determinants framework. Needs do not arise simply as a function of age or as random bad luck. Rather, many conditions and impairments that occur in childhood, working life and older age have a strong social gradient, and several are more prevalent among people from minoritised ethnic backgrounds. The extent to which these conditions give rise to needs for support with daily living is itself influenced by the circumstances in which people live and work, including, for example, the quality of housing. Together, these phenomena produce startling results. In England, someone in their early 30s with no educational qualifications already faces the level of risk of limiting long-standing disability that someone with a

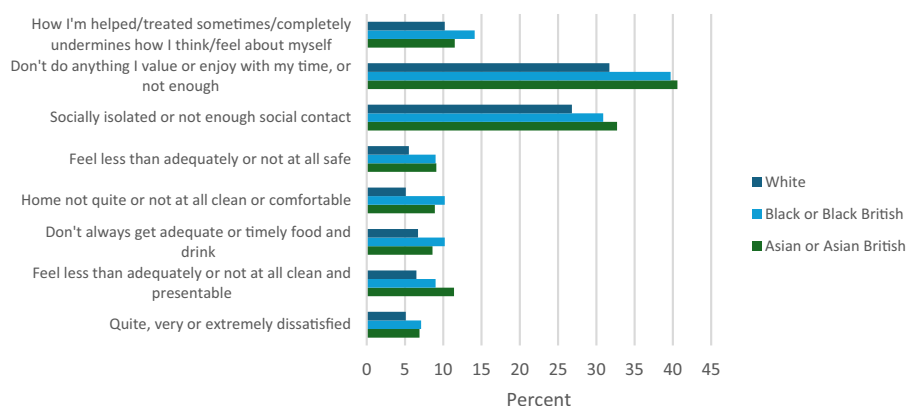


Figure 5. Differences in service users' experience of public formal care by ethnicity, England, 2021–22. *Source:* Author's analysis based on NHS Digital (2022) Personal Social Services Adult Social Care, England - 2021–22: Annex Tables.

Note: In addition to those shown in the figure, results for 'Mixed', 'Other' and 'Not stated' ethnic groups are provided in the published tables, omitted here for clarity of presentation.

degree will encounter only in their late 60s; and a 65–69-year-old in the bottom fifth of the income distribution already has, on average, the level of need for support with daily living that someone in the top fifth of the income distribution will only reach when they are around 85.

Even if needs were equally distributed across the population, inequalities in access would persist unless publicly funded care reached all those who cannot afford to pay privately. But needs are not equally distributed, and the evidence suggests that publicly funded care is often not enough to close the gap: in England, for example, higher-income older people are twice as likely to receive some formal care (public or private) as lower-income people with the same level of need. One consequence is the greater responsibility for providing unpaid support that falls on the families, neighbours and friends of lower-income older people. Given that these unpaid carers are likely (though not necessarily) drawn from the same socio-economic groups as the people they are supporting, this represents a double disadvantage: facing higher risks of developing care needs at a younger age themselves, and being more likely to be called upon to provide support to someone else.

Ethnic inequalities intersect economic inequalities, and this is apparent in the experience of care recipients. Among respondents to England's ASCS, the large majority of whom are low income, Asian and Asian British, and Black and Black British care users across age groups and settings are on average 44 and 48 per cent, respectively, more likely to report poor experience than White respondents. The explanation for these observed differences needs further investigation, but discrimination is a contender.

Economic inequalities, as represented in this analysis by household income, area deprivation or educational qualifications, and social inequalities, as represented in this analysis by ethnicity, permeate all aspects of long-term care: the creation and

prevalence of need; access to formal care and the weight of unpaid care; and the experience of receiving (publicly funded) support. These inequalities can be understood in a framework of social determinants, as represented in Figure 1 and Table 1. Rather than a narrative that describes population ageing, the reduced supply of unpaid care and rising costs for the public purse as the policy problem and better organisation and financing of services as the solution, pursuing a social determinants reframing turns our attention to the multiple drivers of need. It implies selecting the needs of disabled and older people (and their carers) – rather than ageing itself – as the focus, and categorising layers of influences on those needs and how they are or are not met. Services are one, but only one, of those influences. The narrative becomes one primarily of social and economic inequalities, a narrative that is already gaining traction through the ‘care poverty’ approach (Kröger, 2022).

A reframing of this kind has implications for research, practice and policy. In relation to research, rather than presuming ‘age’ as a proxy for need, more investigation is required to understand the mechanisms that lie behind the observed inequalities. What aspects of living and working conditions give rise to higher incidence of impairments and conditions, and how do the environments in which more disadvantaged people live and work mean that the same impairments are more likely to generate a need for support? How do these evolve differently across the lifecourse?

On inequalities in access, more research is needed on how social gradients in access to formal care (public and private combined) vary between long-term care and welfare regimes, and in the context of different degrees of underlying socio-economic inequality. Moreover, the unequal economic responsibility for unpaid care that is a corollary of the unequal distribution of care need with unequal access to formal care deserves attention in its own right, from the perspective of those who are called upon to provide it.

An implication for long-term care practice is a more thorough-going recognition of socio-economic and cultural inequalities: for the person with needs, their support network and in the wider neighbourhood context. In social work with children and families, some practitioners have adopted a ‘poverty aware paradigm’ (Krumer-Nevo, 2016); perhaps something similar could be developed for long-term care. Messer’s (2019) work with frontline practitioners in Germany showed they were aware that some older people had insufficient income to eat well, to participate in social activities, or to follow recommended therapies, but did not know how to respond.

Finally, although long-term care policy is often framed by the preoccupations of ageing and services (and their financing), reforms that do not address socio-economic inequalities in the distribution of need and of unpaid care responsibilities will miss their mark. Neither insurance nor means-tested systems will create a level playing field for access to formal care if the needs-based eligibility criteria they employ are so stringent that the bulk of care continues to be provided unpaid or not at all.

More fundamentally, demand for long-term care is growing, but that is not simply a result of ageing populations and female labour participation, it is also a result of inequalities throughout the lifecourse which give rise to higher risks of needing to draw on support at a younger age for lower socio-economic groups. If all

30 year olds, or all 65 year olds, had the needs profile of the best-educated or highest-income groups currently, demand would be substantially reduced. Tackling the social determinants of long-term care must be central to long-term care policy. This means that long-term care has a major stake in the health inequalities agenda, particularly in relation to those inequalities that give rise to long-term needs. That reaches right back to supporting child and adolescent well-being, including through eradicating poverty. It means that ‘prevention’ should be understood in a lifecourse perspective, not only as early access to home care services (as in England’s Care Act 2014) when needs have arisen. Prevention must include policies on adequate social security, housing quality, occupational health and safety protections and neighbourhood regeneration. Long-term care policy should also lead on creating more inclusive and enabling environments which mean that people with a range of conditions and impairments can live well without requiring additional support. Provision of long-term care *services* – the part that currently preoccupies policy – is a long way downstream.

Supplementary material. To view supplementary material for this article, please visit <https://doi.org/10.1017/S0047279425101220>

Acknowledgements. I thank Nic Brimblecombe, David Piachaud and Polly Vizard at LSE and two anonymous reviewers for their careful reading of, and feedback on, earlier drafts. I am grateful to Selçuk Bedük, Rosella Ciccia, Mary Daly, Aaron Reeves and other members of the Department of Social Policy and Intervention at the University of Oxford for enriching discussion and comments while I was visiting and writing this paper.

Competing interests. The author declares none.

Notes

1 ‘Unpaid’ is not wholly accurate, since carers may receive (modest) cash benefits in recognition of their role. ‘Informal’ seems to imply casual, which is misleading for care that is often sustained 24 hours a day, 7 days a week, over a period of many years. ‘Family care’ is overly restrictive, since friends, neighbours and other members of the community may also play important roles in a support network.

2 The relationship between ‘Needs’, ‘Access’ and ‘Experience’ can also be read in the opposite direction: the experience a person has depends on the services or support they access, and the services or support they access depend partly on their needs. This is not highlighted with arrows in the figure because it is already well understood in the service-driven logic of long-term care policy and research, but it is compatible with the framework.

3 HSE is funded by NHS England and run by NatCen and UCL [University College London] Department of Epidemiology and Public Health, National Centre for Social Research (2023); NatCen Social Research, University College London, Department of Epidemiology and Public Health (2022, 2023). For further details, see NatCen and Social Research and UCL (2020) Health Survey for England 2019: Methods <https://files.digital.nhs.uk/24/190E9D/HSE19-Methods-rep.pdf>

4 Nine ADLs: getting in/out of bed; washing face and hands; having bath/shower (including getting in/out); dressing and undressing (including socks and shoes); using the toilet; eating (including cutting up food); taking medicine (right amount, right times); getting around indoors; getting up/down stairs. Four IADLs: getting out of the house; shopping for food; routine housework or laundry; paperwork or paying bills.

5 Easy-read and translated versions of the questionnaire are provided for those who need them. Only 2% of returns are completed by an advocate on behalf of the service user, but a much larger proportion of respondents say that they received some help from a carer or friend/family member in completing the survey. Response rates are similar for men and women, slightly higher for White (28%) than non-White (22%) ethnic groups, and higher for people of any age with learning disability (37%) and lower for people

aged 65 or over in residential care (19%). Weights have been applied in the analysis reported below to take account of sample design and of non-response by strata within each local authority, to ensure the overall results represent the population of adult social care service users as closely as possible. See NHS Digital (2022a) for further details of survey methodology and NHS (2022b) for the dataset.

6 HSE records five ethnic groups: White, Black, Asian, Mixed/multiple ethnic background, and Other ethnic background. Unweighted sample in this analysis for White 6,379, Black, 82, Asian 179. Despite pooling across three years, sample numbers are insufficient to report separately on Mixed/multiple, or on Other ethnic groups. Results in text are from ordinary least-squares (OLS) regression of number of ADLs or IADLs with which help is needed, on the five ethnic categories and controlling for the age groups shown in Figure 1. Reported differences are statistically significant at the 95% level or higher, and the calculation of standard errors takes account of the complex survey design (in this and all other estimation results reported in this paper). Full specifications and results in online Appendix.

7 OLS regression on number of ADLs or IADLs with which help is needed, on IMD quintile group, controlling for income quintile group, ethnic group and age group. Reported difference is statistically significant at >99% level. Estimation sample 4999 (reduced from full sample due to missing values on some covariates).

8 Data points from Figure 3 in Banks et al. (2023), kindly supplied by the authors. Original data source: UK Household Longitudinal Study 2009–2019.

9 Author's calculation using HSE 2017–2019. Probit regression of 'any formal care received in last week' on income quintile group, age group and number of ADL/IADLs with which help is needed. Predicted probability of receiving any formal care in highest income quintile group 0.052; average marginal effect of lowest two income quintile groups combined is −0.031, statistically significant at >95%. Full specifications and results available in online Appendix.

10 To prevent statistical disclosure, ethnic categories in the version of the dataset that is made available for re-analysis are further collapsed into White and non-White; differences in experience between these broad categories are statistically significant at 95% or above in relation to each of the eight indicators. Full specifications and results available in online Appendix.

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