ESPN Thematic Report on Challenges in long-term care

United Kingdom

2018

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Directorate-General for Employment, Social Affairs and Inclusion
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European Social Policy Network (ESPN)

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The European Social Policy Network (ESPN) was established in July 2014 on the initiative of the European Commission to provide high-quality and timely independent information, advice, analysis and expertise on social policy issues in the European Union and neighbouring countries.

The ESPN brings together into a single network the work that used to be carried out by the European Network of Independent Experts on Social Inclusion, the Network for the Analytical Support on the Socio-Economic Impact of Social Protection Reforms (ASISP) and the MISSOC (Mutual Information Systems on Social Protection) secretariat.

The ESPN is managed by the Luxembourg Institute of Socio-Economic Research (LISER) and APPLICA, together with the European Social Observatory (OSE).

For more information on the ESPN, see:
http:ec.europa.eusocialmain.jsp?catId=1135&langId=en

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Summary

Most social care in the UK is purchased privately or provided informally by families. Total UK annual spending on social care exceeds £16bn (EUR 22.83bn). Total spending on health and health-related social care is 9.9% of GDP, similar to the EU-14 average. Legal responsibility for social care funding and policy is devolved to the four constituent UK countries. Funding comes from national income and local domestic and commercial property taxes. Commissioning services, assessing potential users and determining eligibility are core responsibilities of local authorities in each country.

Despite rising demographic demand and increased costs, since 2010 successive governments have significantly cut local authority budgets, of which the most significant element is adult social care. In England there is evidence of older people not receiving help with essential activities of daily living. Shortfalls in social care services increase pressures on the NHS and on family carers.

Particularly in England, there are major threats to the viability and capacity of both residential and community/domiciliary care providers and the quality of services. Care providers are struggling to recruit, train and retain staff at the same time as meeting major increases in wage bills. They are therefore opting out of local authority contracts and/or concentrating on private purchasers who can be charged higher fees.

Within England, sources of public funding for social care are shifting from redistributive central government grants to greater reliance on local business and residential property taxes. Neither of the latter reflects current or future local needs for social care. The shift therefore risks major inequities in the availability of funding for, and access to, social care, particularly across England.

Although all four UK countries have experienced austerity-driven cuts in budgets for health and social care, there are some differences between them: personal care is free for older people in Scotland; in Wales social care users of all ages pay no more than EUR 80 a week in means-tested charges. Further recently devolved powers are likely to lead to further divergence between Scotland and the rest of the UK in access to publicly-funded care.

Social care funding was a major issue during the May 2017 General Election campaign. The main political parties promised additional funding to maintain current levels of services and/or to protect the assets of the 40% of older people who are currently liable for all their care costs. None acknowledged the need for significant, long-term increases in funding to secure a stable, high quality care market and equitable access to social care for all assessed as needing it. A Green Paper (consultative document) on sustainable funding for England is due in summer 2018, but with no promise of a legislative timetable.

Apart from limited data on health problems and the provision of family care in the decennial UK-wide Census, data on social care is fragmented between the four UK countries and, further, between local authority administrative and activity reports and population social surveys whose main focus is not social care. The potential for linking data on social care to other demographic, economic or outcome data is therefore limited.

1 Description of the main features of UK long-term care system(s)

Across the UK, funding, policies and delivery of long-term care are fragmented and subject to severe financial pressures affecting access, levels and quality of publicly-funded care. Funding pressures reflect long-term demographically-driven increases in demand; new cost pressures; and substantial austerity-driven cuts in the budgets of the local authorities responsible for funding and providing care in domiciliary and residential settings. By 2020, the UK will spend less than 1% of GDP on adult social care, in contrast to other developed countries[1].

1.1 General characteristics

Responsibilities for policies and budgets for health and social care services are devolved to the English, Scottish, Welsh and Northern Ireland (NI) governments. Annual *per capita* public spending on social care in 2014/15 varied from £295 (EUR 337) (England); £435 (EUR 496) (Scotland); £404 (EUR 461) Wales; and £409 (EUR 467) (NI)[2].

NHS clinical, nursing and therapy services are free across the UK; where nursing is provided in residential settings, the NHS contributes to care home fees. Local authorities are responsible for funding and arranging personal ('social') care in residential and domiciliary settings. Access to publicly-funded social care depends on stringent assessments of need, assets/wealth, income and whether relatives/friends can provide care (there is no legal obligation). Usually only people with substantial or critical level needs are eligible. Public funding for help with domestic tasks is not usually available. In addition, the Department for Work and Pensions (DWP) has hitherto been responsible for social security benefits covering extra care expenses and income replacement for family carers, across all four UK countries. The Department for Business, Innovation and Skills is responsible for care-related leave from paid work.

1.2 Principles of governance and system organisation

Local authorities are legally responsible for assessing population-level and individual care needs and ensuring appropriate support is available, in residential or domiciliary settings or from family carers. Local authorities have considerable discretion over eligibility and provision; despite some standardisation of assessment processes and eligibility thresholds, levels and patterns of services vary between localities. DWP care and carer benefits are allocated through separate UK-wide eligibility and assessment arrangements.

In **England** since the early 1990s social care provision has been transformed into a quasi-market dominated by for-profit and charitable providers funded by local authorities; 89% of domiciliary services and 94% of residential beds[3] for older people are supplied by private providers. The residential market in particular is dominated by several large chains backed by private equity capital and reliant on risky financial structures.

The *Care and Support Act 2014* introduced a new legal framework for English local authorities, including duties to prevent or delay needs for care; the promotion of wellbeing through the provision of care services; oversight of local care markets; and new a strengthened duty to assess the need of family carers. The Act also proposed a

[1] Humphries, R. et al (2016) *Social Care for Older People*, London The Kings Fund and Nuffield Trust

[2] www.health.org.uk *Health and Social Care Funding Explained*, accessed 27.March 2018.

[3] CHPI (2016) *The Failure of Privatised Adult Social Care in England: What is to be done?* Centre for Health and the Public Interest.

new framework for funding care, with a 'cap' on the lifetime amount a person pays towards their care (see below).

In **Scotland,** everyone aged 65+ is entitled to free personal care. Those in residential care or nursing homes receive £171 (EUR 195) towards their personal care and £78 (EUR 89) for any nursing care. Since 2016, budgets for adult social care, primary healthcare and some secondary health services have been combined. New combined integration authorities coordinate health and care services and commission NHS boards and councils to deliver services[4].

Following the 2014 independence referendum, in 2018 responsibility for 11 DWP social security benefits, including care and carer payments, is devolved to the Scottish Government. In future, assessments for these benefits may be aligned with assessments for social care, so eligibility criteria and benefit levels may vary between Scotland and the rest of the UK.

Wales has capped user charges for home care (all client ages), to £70 (EUR 80) a week[5].

Health and social care budgets and services in **N Ireland** are integrated under five health and social care trusts. For people aged 75+, most personal care at home is free. Those under 75 may have to pay towards their care, depending on local trust policy.

1.3 Types of financing

NHS elements of long-term care (including nursing care in residential settings) are funded from general taxation and free of charge. Local authority funding for social (personal) care comes from a mix of redistributive central government (general taxation) grants and local business and property taxes; the balance between these is changing (see below).

Individuals make significant contributions to total social care spending. In England, those with assets over £23,250 (EUR 26,500) pay the full costs of residential care; below £14,240 (EUR 16274) the local authority pays in full (between these upper and lower limits costs are split). Assets include the value of a home; there are exceptions if close relatives occupy the home. Otherwise the forced sale of property that would otherwise be inherited is deeply unpopular. Two-fifths of care home residents fund the entire cost of their care; a further 14% 'top up' local authority funding with additional private payments. Between 6%-25% of people in England receiving care at home purchase all their care privately and a further 200,000 also purchase help with domestic tasks, possibly in addition to publicly-funded personal care[6]. Many of those eligible for local authority-funded care at home also pay means-tested client charges.

1.4 Balance between institutional, domiciliary and cash support

There has been a steep reduction in numbers receiving publicly-funded domiciliary and community services – in England down 30% from 2009/10 to 2013/14, compared with just 4-6% fewer receiving residential care[7]. Currently accommodation and care is provided in around 16,000 English residential care locations, with the capacity to provide

[4] Accounts Commission (2016) Changing models of health and social care, downloaded from http://www.audit-scotland.gov.uk 02 Oct 2017.

[5] Age Cymru (2017) *Paying for Care and Support at home in Wales*, downloaded 17 January from www.ageuk.org.uk

[6] Baxter, K. and Glendinning, C. (2014) P*eople who fund their own social care: A scoping review,* SSCR 2619, NIHR School for Social Care Research, SPRU, University of York. These figures come from formal home care service providers; it is not known how many people may be employed through wholly private arrangements.

[7] Humphries, R. et al (2016) *Social Care for Older People*, London The Kings Fund and Nuffield Trust

care for around 460,000 people. Half a million adults receive publicly-funded care services at home[8].

People eligible for local authority care at home can be offered personal budgets (PBs) – individualised funding allocations – to be used to pay for customised services in line with individual preferences. PB users are still liable for means-tested user charges. The use of PBs is tightly restricted to activities agreed with the local authority and expenditure is closely monitored. However, for most older people (given their high level care needs), PBs are usually retained by local authorities and used to pay for local authority-commissioned in-kind services.

1.5 The role of family care

Family carers carry growing responsibilities. UK-wide, numbers of carers increased by 11% between 2001 and 2011[9]. Growing numbers of family carers are themselves elderly; 20.5% of people aged 65-plus are carers. Older carers are also amongst those most likely to provide very high levels of care, especially those aged 80-plus caring for co-resident partners.

English carers have not benefitted from the measures in the 2014 Care Act; many local authorities actually carried out fewer assessments of carers' needs in the year following the Act than before. One in five carers providing 50+ hours of care a week has no support for this role[10]. Working age carers have rights to request flexible working arrangements and to 'reasonable' time off work to deal with crises involving a dependent.

1.6 Future projections of care needs

Numbers of older people are increasing more rapidly than the population in general; by 2030 numbers aged 85+ in England will have doubled. However, there will be fewer children available to care for frail elderly parents, leading to greater reliance on care by partners or more distant relatives and friends, and increasing numbers with no informal care at all[11]. By 2019/20, a £2.8bn (EUR 3.2bn)-£3.5bn(EUR 4.0bn) gap is expected between resources and demand for care.

2 Assessment of challenges in long-term care

2.1 Access and adequacy of publicly-funded care

In all four UK countries, access to social care is increasingly restricted. Since 2010 'austerity' policies have severely cut budget allocations from the (UK) Westminster government to the devolved administrations and the local authorities within them. These cuts have taken place despite rising demand and increased costs.

In **England,** between 2011/12 and 2015/16, spending on adult social care (excluding resources transferred from the NHS) dropped by 17%[12] - while the population aged 65-plus grew by 15.6%. Over 80% of local authorities cut real terms spending on older people's care[13].

[8] CQC (2017) The State of Adult Social Care Services 2014 to 2017, Care Quality Commission downloaded from http://www.cqc.org.uk/ 17 January 2017.

[9] Carers UK (2014) *Facts about Carers: Policy Briefing*, Carers UK London downloaded 8 June 2015.

[10] CQC (2016) *The State of Health Care and Adult Social Care in England 2015/16,* London: Care Quality Commission, www.cqc.org 15 October 2016.

[11] Pickard, L. et al (2012) Mapping the Future of Family Care: Receipt of Informal Care by Older People with Disabilities in England to 2032, *Social Policy and Society,* 11 (4):533-45.

[12] Health Foundation, *Health and Social Care Funding Explained*, www.health.org.uk, accessed 28 March 2018.

[13] Humphries, R. et al (2016) *Social Care for Older People*, London The Kings Fund and Nuffield Trust

In **Scotland** local authority budgets have been cut by 11%; gross *per capita* social care spending fell by over 3% between 2009/10 and 2013/14[14].

Welsh real terms *per capita* spending on social care fell by 13% between 2012 and 2017. Spending on care services will need to rise by £184m (EUR 210m) a year in current prices just to meet demographic and cost pressures. Restoring pre-austerity (2009/10) levels of spending on older people's care would require similar further additional funding[15].

It is difficult identifying social care funding changes in **Northern Ireland,** as the Province receives an integrated health and social care budget from Westminster. *Per capita* spending seems to have been relatively stable since 2011/12. However the NI Health Boards recently proposed cuts in residential home admissions and domiciliary care[16]. Although extra funding was promised as part of the 2016 agreement between the minority Westminster Conservative government and the NI Democratic and Unionist Party, this has been held up by ongoing political stalemate over the restoration of the Stormont Executive[17].

As well as funding cuts, there are new cost pressures from the phased implementation of a higher legal minimum wage ('National Living Wage', NLW) between 2016 and 2020. In a notoriously low pay sector, the NLW significantly increases care providers' wage bills, plus pressures on local authority budgets as the largest purchasers of care. Pay pressures including the NLW remain the major driver of cost increases in 2017/18[18].

Far fewer people now receive publicly-funded social care and there is extensive unmet need. An estimated 1 in 8 older people now lack help with vital everyday care tasks, including just under 1 in 5 who need help with bathing, getting out of bed or using the toilet but receive no help[19].

Lack of social care is argued to have a major impact on hospitals, causing increasing numbers of emergency admissions and significant delays in discharging patients who have finished treatment. Between 2013 and 2015, there was a 31% increase in hospital bed use by patients awaiting discharge[20]. Delayed discharge has also been linked to increased mortality rates[21].

2.2 Quality of care

All providers of residential, domiciliary and community-based care services must register with an independent regulator – in England the Care Quality Commission[22] - which undertakes routine monitoring and regular inspections. The latter reveal significant quality shortcomings; in 2015/16, 26% of social care services needed improvement. Care quality in nursing homes is particularly poor, with over 40% rated inadequate or needing

[14] http://www.scvo.org.uk/news-campaigns-and-policy/scotlands-social-care-sector-the-financial-evidence-that-is-driving-change/

[15] WPS (2017) *The Future Funding of Health and Older Adult Social Care in Wales,* Wales Public Services 2025, downloaded from http://www.walespublicservices2025.org.uk/2017/05/30/the-future-funding-of-health-and-older-adult-social-care-in-wales/

[16] *Key points of the health trusts' £70million cost-saving proposals,* www.bbc.co.uk/news/uk-northern-ireland-41037895, accessed 28 March 2018.

[17] http://www.belfasttelegraph.co.uk/news/northern-ireland/hospitals-face-70m-budget-cuts-as-stalemate-holds-up-vital-funds-36046967.html, downloaded 02 October 2017.

[18] ADASS (2017) *Budget Survey 2017,* downloaded from https://www.adass.org.uk/adass-budget-survey-2017 3 October 2017.

[19] Age UK (2017) *Briefing: Health and Care of Older People in England 2017* London Age UK.

[20] NAO (2016) *Discharging Older Patients from Hospital, National Audit Office* 26 May HC18.

[21] Green, M. et al (2017) Could the rise in mortality rates since 2015 be explained by changes in the number of delayed discharges of NHS patients? *Journal of Epidemiology and Community Health*, Online First, published on October 2, 2017 as 10.1136/jech-2017-209403.

[22] www.cqc.org.uk

improvement. In autumn 2017 over 80% of local authority directors reported concerns over the quality of local care services[23].

Despite a 30% reduction in adult social care jobs since 2012[24], English care providers report increasing problems recruiting and retaining staff. Staff turnover has been increasing since 2012-13 and in 2016-17 reached 27.8%. The vacancy rate in 2016-17 for social care jobs was 6.6%, well above the national average of 2.5%-2.7%; nursing vacancy rates in English care services are 9%. No qualifications are required for ordinary care work and 70% of English local authorities exclude training costs from the fees they pay providers[25]. English government auditors have expressed concern over the lack of national or local workforce strategies and the poor opportunities for career progression[26].

2.3 Workforce challenges

Growing demand for informal, family-based care impacts on carers' employment. English survey data shows that caring for as little as 10 hours a week has a negative impact on labour market participation[27]. Carers' ability to combine work and care depends on receipt of formal services such as home care, day or respite care[28]. However, there is considerable unmet need for such services; carers report the non-availability of appropriate, good quality, reliable services and, consequently, their unwillingness or the unwillingness of the older person to accept what is available[29]. There are no national initiatives to enable family carers to convert their care-giving experience into formal labour market qualifications.

2.4 Financial sustainability

Both residential and domiciliary care providers are struggling, as local authorities have frozen, cut or offered below-inflation increases in the fees they pay for services. Most residential homes now charge substantially higher (average 43%) fees to private paying residents in order to cross-subsidise below-cost local authority-funded residents. Home care providers are reported to have stopped bidding for local authority contracts, handing back contracts or ceasing to trade. During 2016/17, 69% of English local authorities reported one or more local care provider closing down or handing back contracts[30]. By autumn 2017, over 50% of local authorities reported difficulty finding a nursing home place, 46% had difficulty purchasing home care and 20% reported difficulty finding a residential home place[31].

In early 2018, as local authorities set their budgets for 2018/9, 80% of English local authorities reported anxieties about their financial sustainability (one has already

[23] ADASS (2017) *Autumn Short Survey of Directors of Adult Social Services 2017,* downloaded from www.adass.org.uk 16 January 2018.
[24] The Guardian 8 February 2017
[25] House of Commons Communities and Local Government Committee (2017) *Adult Social Care,* Ninth Report of Session 2016-17., HC 1103, House of Commons.
[26] NAO (2018) *The Adult Social Care Workforce in England,* London National Audit Office.
[27] King, D. and Pickard, L. (2013) When is a carer's employment at risk? *Health and Social Care in the Community,* 21 (3): 303-14.
[28] Pickard, L. et al (2017) 'Replacement care for working carers? A longitudinal study in England 2013-15, *Social Policy and Administration* First published: 16 August 2017 https://doi-org.libproxy.york.ac.uk/10.1111/spol.12345

[29] Brimblecombe, N. et al (2017) Barriers to receipt of social care services for working carers and the people they care for, *Journal of Social Policy* 47 (2):215-33
[30] ADASS (2017) *Budget Survey 2017,* downloaded from https://www.adass.org.uk/adass-budget-survey-2017 03 October 2017.
[31] ADASS (2017) *Autumn Short Survey of Directors of Adult Social Services 2017,* downloaded from www.adass.org.uk 16 January 2018.

declared bankruptcy); 40% reported planning further cuts in adult social care budgets; and all faced uncertainty over sources and levels of funding beyond 2020[32].

3 Recent/planned reforms and how they address the challenges

Policy responses to the funding crisis have been piecemeal; short-term, crisis-driven; and likely to increase inequity both between countries and the local authorities within them.

3.1 Better Care Fund (BCF)

In England, since 2010/11 some resources have been transferred from the NHS budget to local authorities. The BCF is intended to incentivise closer collaboration and service developments at the interface between social care and the NHS. However, during 2016/17 almost 80% of the BCF was spent on maintaining existing services rather than new investment, thus failing to achieve either efficiency savings or better patient outcomes[33]. The spring 2017 Budget allocated a further £2bn (EUR 2.28bn) to the BCF up to 2019/20, to be spent on social care services that reduce pressure on the NHS and/or stabilise the social care provider market[34].

3.2 Council Tax 'precept'

Between 2016/17 and 2019/20, English local authorities have been permitted to increase local residential property taxes (Council Tax) by an additional amount above baseline, with the extra 'precept' ring-fenced for spending on social care. However, the total raised by the precept in 2016/17 failed even to cover the new NLW costs[35]. In 2017 the 'precept' was re-profiled, allowing local authorities to raise Council Tax up to 2.99% in 2018/19, plus a further 3% precept ring-fenced for social care. This is expected to raise just £250m (EUR 285m) towards a funding gap of £5.8bn (EUR 6.6bn)[36].

3.3 Reforms to Business Rates

Between 2016/17 and 2019/20, English local authorities will keep increasing proportions of local business taxes, rising to 100% by 2020 - but will lose £6.1bn (EUR 7.0bn) of redistributive central government grants[37]. This is intended to incentivise local investment but is again unrelated to local care needs. A Government review to devise a fair funding formula appears to have stalled[38].

A further £150m (EUR 169m) was announced in early 2018 as part of the 2018/19 English local government funding settlement, for spending on adult social care.

[32] LTIU/MJ (2018) *State of Local Government Finance Survey*, downloaded from www.lgiu.org.uk/report/lgiu-mj-state-of-local-government-finance-survey 10 February 2018.
[33] NAO (2017) *Health and Social Care Integration,* London: National Audit Office, downloaded (11 Feb 2017) from www.nao.org.uk.
[34] ADASS (2017) *Budget Survey 2017,* downloaded (3 Oct 2017) from www.adass.org.uk/adass-budget-survey-2017
[35] ADASS (2016) *Budget Survey 2016* downloaded from https://www.adass.org.uk/budget-survey-2016
[36] 'Councils allowed to raise tax to fund social care', *The Guardian,* 20 December 2017
[37] Harris, J. (2015) 'Will the rot stop when even the parks are flogged off?', *The Guardian,* 27 November 2015
[38] Hetherington, P. (2017) 'How will councils survive the funding abyss?' *The Guardian* 5 September 2017

3.4 Assessment of recent policy reforms

Both Business Rate reforms and the Council Tax 'precept' leave local authorities much more dependent on their local tax base, despite variations in tax-raising capacities that are inversely related to local demand for social care. Local authorities with more poorer older people, and thus greater demand for publicly-funded care, can generate less additional revenue. Nine out of ten local authorities, and a Parliamentary Committee of Inquiry, believe Council Tax increases are neither viable nor equitable ways of meeting the social care funding gap, particularly in poor areas with high levels of need.[39],[40]. Nevertheless, the increased reliance on local sources of funding mean it will be increasingly difficult to deliver consistent levels of access to and standards of care services across the country[41].

4 Policy Recommendations

Debates about reform to care funding have been on-going for over two decades. Three priorities are clear: first, an urgent injection of additional funding to address the current crisis in the availability and quality of care (and the consequent impacts on care providers and the NHS); secondly, longer-term, sustainable reforms to ensure funding continues to grow in line with anticipated demographic pressures; and thirdly, measures to ensure the equitable distribution of resources, at least within countries, to reflect local variations in need.

The English 2014 Care Act included proposals to cap the amount an individual pays for care over her/his lifetime. This would not increase the overall budget for social care; depending on the level of the cap the redistributive effects could be small, mainly benefitting those older people with high needs and modest assets[42]. In the context of 'austerity' policies, implementation (originally due in 2016) was postponed until after 2020.

Social care funding became a major issue during the June 2017 General Election. All three main political parties promised some additional funding to maintain current levels of publicly-funded care and/or protect the assets of more affluent older people currently liable for all their care costs through the introduction of a cap[43]. None apparently recognised the need for significant, long-term funding increases to secure a stable, high quality care market and equitable access to social care for all assessed as needing it.

There are growing pressures for new policies to ensure funding sustainability, for example through a social insurance approach[44,45]. A Green Paper (consultation document) on funding options is promised for summer 2018. This is likely to restate the commitment to a cap on individual expenditure. However, given the lack of a Parliamentary majority for the current government, continuing differences of policy between the main political parties plus the demands of Brexit, new legislation seems unlikely to be imminent. In addition, attention is needed to the impact of Brexit on the care workforce; 7% of care workers are from other European Economic Area countries and 9% from non-EEA countries. Restricting recruitment from overseas would have a

[39] House of Commons Communities and Local Government Committee (2017) *Adult Social Care,* Ninth Report of Session 2016-17, HC 1103, London: TSO

[40] LGIU (2017) *State of local government finance survey,* downloaded from http://www.lgiu.org.uk/reports (11 February 2017)

[41] Amin-Smith, N., Phillips, D. and Simpson, P. (2018) *Adult Social Care Funding: a Local or a National Responsibility*? London: Institute for Fiscal Studies.

[42] Humphries, R. (2013) Paying for Social Care: Beyond Dilnot, London, Kings Fund.

[43] CHPI (2017) *Social Care Funding. Understanding the reality behind the Manifesto Commitments,* Centre for Health and the Public Interest, May.

[44] ADASS (2017) *Autumn Short Survey of Directors of Adult Social Services 2017,* downloaded from www.adass.org.uk 16 January 2018.

[45] House of Lords (2017) *The Long-term Sustainability of the NHS and Adult Social Care*, HL Paper 151

major impact on recruitment in London and SE England, where almost 40% of the care workforce are non-British born[46].

Meanwhile, in further fragmentation across the UK, Scotland will use its devolved powers to increase the level of Carers Allowance – an income replacement benefit for family carers – from summer 2018, at an annual cost of £30m(EUR 34m)[47].

5 Analysis of indicators for measuring LTC

5.1 Types of data

There are two main data sources: local authority administrative and activity data; and data derived from national population (or population subgroup) surveys.

Administrative data includes aggregate statistical returns from local authorities on topics such as numbers of assessments and reviews; numbers of service users and carers receiving support; expenditure; unit costs; and user experiences. Data is restricted to social care use funded by local authorities and excludes care purchased privately without local authority involvement[48].

Survey data is normally been collected as part of a wider remit[49]. Thus it is often possible to link data on needs for, or use of, paid and/or unpaid care with other variables in the survey such as age, gender, ethnicity or housing.

5.2 Adequacy of data

There is robust evidence, derived from both administrative and survey data, on the increasingly restricted access to publicly-funded care and the resulting unmet care needs in England. Administrative data from routine monitoring and inspection activities provides some evidence on the quality of care from formal service providers; this includes care received by private purchasers as well as publicly funded users. However, there is no data on the quality of care purchased care privately in the grey market or provided by relatives/friends.

Evidence on the sustainability of care is also not robust or consistent, although English local authorities are beginning to report provider market failures in their areas. The UK Census includes questions on the provision of unpaid care and thus captures (self-identifying) people of all ages caring for others of all ages. However, it does not include questions on the impact of caring responsibilities on employment. Data on receipt of Carers Allowance, an income replacement benefit for non-employed carers, is unreliable because of the benefit's strict eligibility criteria.

Finally there is little comparable data covering all four UK countries. The decennial Census and a couple of population surveys provide estimates of the prevalence of disability/limiting health conditions across the UK. However, administrative data on the use and experiences of social care is country-specific, offering little opportunity to compare outcomes across the four UK countries. Data on the experiences and outcomes of people who fund their own care privately is also limited[50]. Given the growing size of the private care market, this is a significant shortcoming.

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[46] NAO (2018) *The Adult Social Care Workforce in England,* London, NAO.

[47] '*Increased Carers Allowance to be delivered next summer'* downloaded (10 January 2018) from https://news.gov.scot/news/social-security-benefits

[48] Data for England is published at www.hscic.gov.uk.

[49] Many survey data sources are available at www.ukdataservice.ac.uk.

[50] Baxter, K. and Glendinning, C. (2015) *People who Fund their Own Care*, NIHR SSCR.

A recent review[51] of English data sources (see Appendix) concluded that data on social care is considerably more limited than on other welfare sectors such as housing or income maintenance. These limitations may reflect the fragmentation of responsibilities for arranging and funding care between the four UK countries and, within England, between 152 local authorities; and the fragmentation of responsibilities for delivering care, between thousands of private service provider organisations, privately employed 'grey' care workers and over 5 million (England) unpaid family care-givers. Even within England, no single agency holds administrative data for all social care and there is no single comprehensive data source.

The scope for linking data on adult social care is also limited. Links between Census and death and cancer registration data can enable research into survival rates of care home residents and unpaid carers. It is also possible to link the Health Survey for England, the English Longitudinal Study of Ageing and data on hospital admissions, to investigate relationships between receipt of community-based services and hospital admissions by older people. However, as local authority administrative data is not collected at an individual level, it cannot be linked with other administrative or survey data, such as health care usage.

[51] King, D. and Wittenberg, R. (2015) *Data on Adult Social Care*, NIHR School for Social Care Research.

Appendix: Sources of data on social care (England)

DATA SOURCE	TOPICS
Adult Social Care activity data	Referrals and assessments, receipt of publicly-funded residential and community services. Annual; English local authorities.
Adult Social Care Survey	Experiences and outcomes for people using English local authority-funded services. Annual.
Adults with Learning Disabilities in England	Experiences of adults with learning disabilities across a range of services, health and wellbeing. Survey conducted 2003-4 of adults in private households and supported accommodation; England only.
Census	Disability among adults and older people, provision of unpaid family care, receipt of residential care. UK wide; conducted every 10 years; last wave 2011.
English Longitudinal Study of Ageing	Disability and cognitive impairment among people aged 50+; provision and receipt of unpaid care by older people. England; bi-annual, since 2003.
Family Resources Survey	Disability and cognitive impairment among older people; provision and receipt of unpaid care by older people. Annual; cross-sectional; UK-wide (NI included since 2002/3).
Health Survey for England	Disability, provision and receipt of unpaid care, receipt of community services and payment for care by older people. Annual; adults all ages; England only.
Laing and Buisson surveys	Expenditure and unit costs among social care providers.
National Minimum Data Set for Social Care	Adult social care workforce; care providers. Covers about half the care workforce; England only.
Personal Social Services expenditure and unit costs data.	Payment for care; expenditure and unit costs. Annual data from English local authorities.
Personal Social Services Survey of Adult Carers in England	Provision of unpaid care; carer experiences and outcomes. English local authorities; repeated bi-annually since 2009.
Survey of Carers in Households	Provision of unpaid care; carer experiences and outcomes. Cross-sectional population survey conducted 2009/10; England only.
Understanding Society – UK Household Longitudinal Study	Disability among older and working age adults; provision of unpaid care. UK-wide longitudinal household survey; adults all ages.