

Toward a new start and a sustainable future for adult social care

Colin Slasberg¹ and Peter Beresford²

¹ Independent Consultant in Social Care

² Professor of Citizen Participation, Essex University

Abstract

The social care system in England is widely seen to be suffering from a sustained period of underfunding as a result of a decade of austerity. Less well observed is that it is also suffering from a chronic lack of direction. The evidence leaves little room for debate that the high transformative ambitions of the personalisation strategy have failed. The ambitions remain ones that have universal support – a service that responds to each individual, enables wellbeing and good quality of life and makes best use of public resources. The question, therefore, is how to achieve this? This paper explores the predominant thinking of the sector's leadership, highlighting its inability to fill the present intellectual vacuum. It goes on to explore how the thinking from the service user movement, notably the idea of independent living, holds the promise of authentic and sustainable change.

Keywords: independent living, social care strategy, funding, eligibility, rights

Context

It is now over a decade since the UK Government's personalisation strategy was launched (Department of Health, 2007). The evidence is that it has not achieved its mission of transforming social care into a system that is fair, where people are in control of their care and support, which enables them to lead fulfilling lives. A survey of over 1,000 service users and carers (Think Local Act Personal, 2017) asked if their views were listened to, and found 70% thought their own views were either not listened to at all, or rarely, or at best only sometimes. The reduction in government grants to local authorities has resulted in an even greater postcode lottery. In 2017/18, after allowing for regional price differences, the highest spending councils spent £21,400 per service user and the lowest £11,400 (Slasberg, 2018).

Think Local Act Personal (TLAP), the body charged by Government to promote delivery of the agenda, is now into its second iteration of a programme they have called *Making it Real* (Think Local Act Personal, 2019). The title is a tacit recognition that the original policy, built on the foundations of the personal budget strategy, has not delivered as it was intended to. The TLAP strategy is based on a series of statements of good intent and invites organisations to sign up to them. At the time of writing, from the TLAP website only 5 of the 152 English local authorities appear to have signed up.

Although the phrase 'personal budget' is now embedded in the adult care sector's vocabulary, its meaning is now taken from the Care Act itself rather than the policy definition. It is thus nothing more than a financial costing exercise that takes place following all the key decisions, not an upfront sum of money for the service user to directly plan their own support (Slasberg, 2017). The sector is encouraged to promote 'strengths-based practice' (Baron *et al.*, 2019) in a recognition that the system is failing, given its focus on deficits thus creating dependency.

Much like the Community Care reforms of the 1990s which had similar ambitions, the personalisation strategy has come and gone, leaving the service largely unreformed and with little more than different language to describe it. A vacuum has been created. If the ambition of creating a system that is fair, empowering and makes the best use of public money still burns bright, to where should it turn next?

The following analysis is divided into two parts. The first identifies the key ideas being pursued by sector leaders. This focuses on two approaches – more money as the solution, and individual behavioural change in the form of ‘strengths-based practice’. The second part identifies strategies that originate from service users themselves. This focuses on the philosophy of *independent living*, with one approach making it a legal right, and the other as the driving vision within a budgeted system.

Ideas from the sector’s perspective

More money

The Local Government Association, which represents the interests of local authorities, produced a report in preparation for the long delayed Green Paper on the future of social care (Local Government Association, 2018) which it followed up in a further report in 2019 (Local Government Association, 2019). Its basic premise is that the social care service is in good shape, but it needs greater financial backing. The report claims funding levels threaten ‘the great progress that has been made in challenging circumstances’ (p.42), and people working in local government ‘take pride in the role it plays in supporting people’s lives’ (p.12). Maintaining the message, against all the evidence (Slasberg & Beresford, 2016), contesting that the personalisation strategy has worked, the report proposes that the Care Act 2014 ‘promotes personal budgets and direct payments in order to give people choice and control over their care’ (p.47). Nevertheless ‘councils are increasingly struggling to even meet the ‘letter’ of the law’ (p.48).

The report identifies underfunding as the outstanding issue. In addition to £1.4 billion required to pay a fair price to providers, the Local Government Association says £5 billion is required to meet both unmet and under-met need. Unmet need is when people are excluded by the system altogether, and under-met need is where people are in the system but have insufficient support to lead the lives they want, and which the system might be expected to provide.

A system that denies there is a funding gap

This analysis runs into serious difficulties. The first is that the eligibility mechanism means the system denies *any* needs are unmet. Once a council deems a need ‘eligible’ it becomes a legal duty for the council to meet it. Councils have to square this reality with the equally powerful fiduciary duty to spend within budget. The conundrum is resolved by flexing the eligibility criteria locally to control the flow of eligible need to that which can be afforded. Any need which is not affordable is reduced to a want, or preference or wish, which the council has no responsibility to meet.

A recent case in Barnet (Disability News Service, 2019) exemplifies the process and the problem. The council sought to save £425,000 by placing people who required support at home in residential care if this would cost less. It was able to do so by declaring that residential care meets the ‘need’ while remaining at home is merely a ‘preference’. This is a view of ‘need’ that flies in the face of what most people are likely to view as needs for dignity, independence, identity and control. It also flies in the face of needs for wellbeing, as set out in section one of the Care Act (HM Government, 2014), which identifies nine core elements of wellbeing. These include emotional wellbeing, being in control of one’s life, being in control of one’s support, dignity and living in a place that is suitable. Most people are likely to agree these elements of wellbeing are better served living in one’s own home rather than an institution, thus making living in one’s own home a need that can be countermanded only in circumstances when wellbeing would demonstrably be better served by living in an institution.

The eligibility system’s circular definition of ‘need’ means that the system cannot recognise either unmet or under-met needs. In 2012, Paul Burstow, as Minister for Care, challenged over the funding gap in social care – which some members believed was as much as £7 billion –

denied there was any funding gap (Health Select Committee, Response to Q.544, Health Select Committee, Ev.108, 17 January 2012). In 2018, the same Committee nevertheless indicated:

Authoritative sources in the social care sector say that, despite the additional funding, there will be a funding gap of £2.2–£2.5 billion in 2019–20. (Housing, Communities & Local Government and Health & Social Care Committees, 2018, para 20)

A little later in 2018, Sir Chris Wormald, Permanent Secretary, Department of Health and Social Care, repeated the official message (Oral Evidence: The Interface between Health and Social Care, HC 1376, 18 July 2018, Public Accounts Committee, 2018). He told the Committee that:

With the exception of the one local authority (Northamptonshire) in which we have intervened, we do not have any evidence that any local authority is not meeting the floor that Parliament set (i.e. to meet their statutory responsibilities under the Care Act).

(Public Accounts Committee, *op cit.*, Q.82)

Why should Government heed the message?

How will sector leaders persuade Government to heed their message that more money is needed to meet what they have hitherto decreed not to be 'need'? The current government has acknowledged the need for more money, but only to prop up the current system. It has referred any debate about the long-term future to cross-party talks (Hancock, 2019). The sector's problem in getting Government to listen to the need for money over and above this is particularly problematic when the current political priority is the balance of public and private funding, with public and media concern about some people having to sell their homes to pay for their care.

Will more money work anyway, without system change?

But perhaps an even more damning indictment of the 'more money' solution is what the 'postcode lottery' tells us. Its existence was highlighted in 2011 by the Dilnot Commission (Commission on Funding of Care and Support, 2011, p.16) which found councils providing 'very different' levels of support for people with similar needs. Phillips & Simpson, in 2017, suggested that disparities had grown under austerity, given that the large cuts to government grants to local authorities had very different impacts on local councils, depending on demographics and the extent to which the council relied on central government grants for a higher proportion of their overall budget. The tenth of LAs making the biggest cuts to adult social care spending per adult saw an average cut of 31%, whilst the tenth making the biggest increases saw spending increase by 7% per adult, on average (Phillips & Simpson, 2017, p.28).

Data published by NHS Digital (<https://digital.nhs.uk/data-and-information/areas-of-interest/social-care>) include data on populations served, number of service users receiving continuing support during the year, and gross spend on people with continuing support, and unit costs of care in the various regions in England. This provides the information for the following analysis.

Equity is usually measured by spend per head of population. However, this is not a good test as populations vary hugely in the demand they make on social care. This is particularly the case in relation to older people. Services in more deprived communities serve significantly more people per head of population. The most significant factor is likely to be the means test effectively excluding more people in less deprived areas. Better health levels in such areas may be another factor. The different levels of demand would mean that two councils with identical budgets per head of population would provide potentially very different levels of support on average to their service users, if the populations they serve have different deprivation levels.

Figure 1 is a scattergram that shows the relationship of deprivation levels to demand from older service users in 2018. Deprivation is measured by the Index of Multiple Deprivation (IMD), which is the average deprivation score for each upper tier council's small areas (<https://www.gov.uk/government/statistics/english-indices-of-deprivation-2019>). The specific source is File 11 of English Indices of Deprivation, published 26 September 2019.

The numbers of service users are taken from the NHS Digital Activity and Finance Report (<https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2018-19>). The specific source is Table 36 of SALT & ASCFR Reference Tables. The IMD scale is from 5.8 as the most affluent upper tier authority (Wokingham) to 42 as the most deprived (Blackpool).

A more reliable measure of geographical equity than spend per head of population is, it is suggested, the *average spend per service user*. This shows the level of support people with similar needs can expect from different councils.

NHS Digital Activity and Finance Report (Tables T34, T41 and T42) shows the number of long-term service users and the gross spend on them (**Figure 2**). It also reports on the unit costs for each service area for each region (Tables T49, T51 and T52). Dividing each council's gross spend in each service area by the relevant unit cost for their region and multiplying by the national average unit cost for that service area enables all spend to be adjusted to the national average.

Figure 1. Older service users per 100,000 population for each council, against deprivation levels 2018/19. (Sources: NHS Digital Activity & Finance Report, *op cit.* and English Indices of Deprivation, *op cit.*).

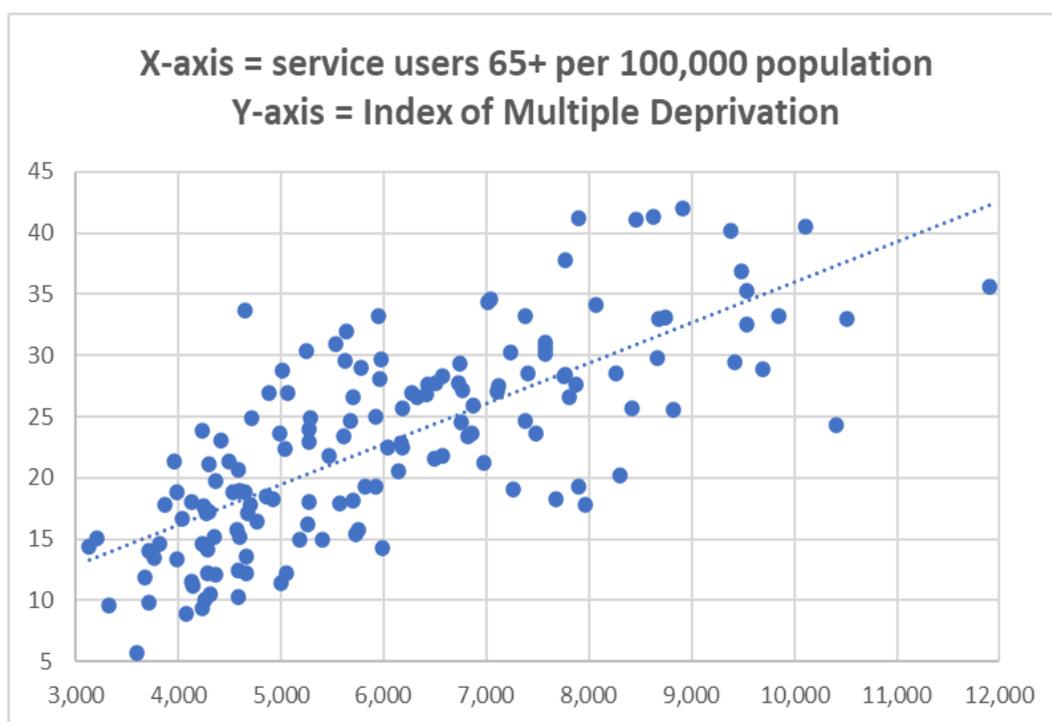
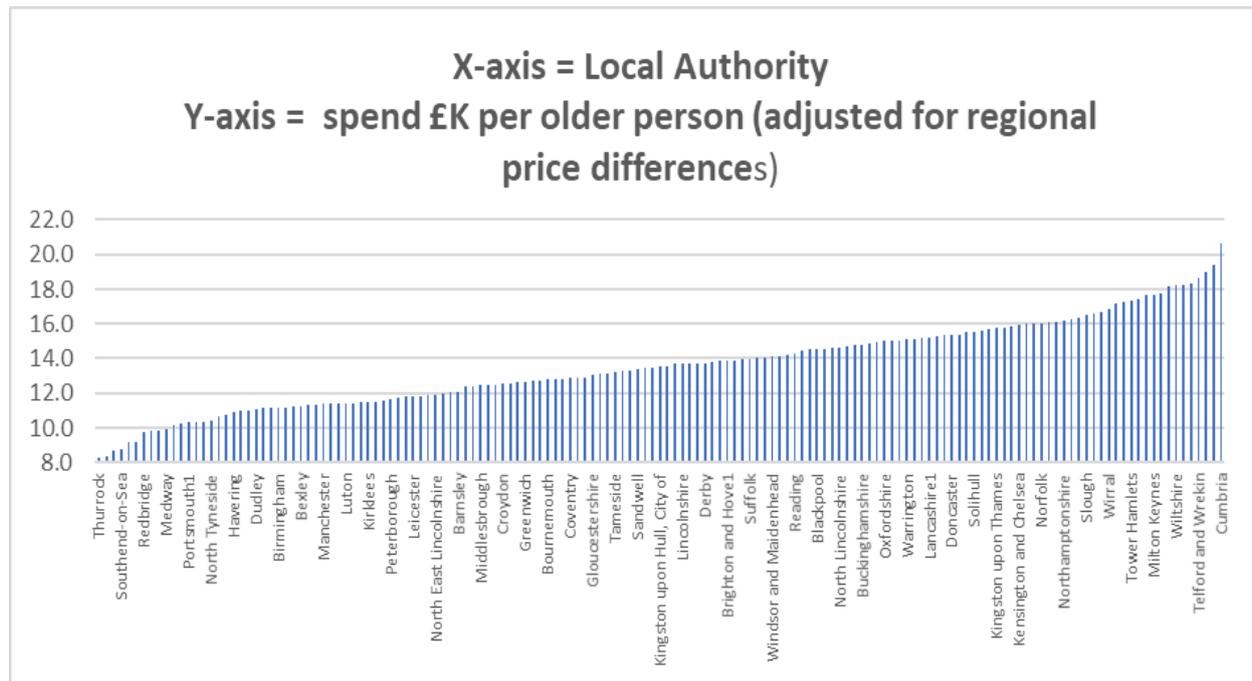


Figure 2. Gross spend per older service user 2018/19. Source: NHS Digital Activity & Finance Report (Tables T34, T41, T42, T49, T51 and T52).



Using this adjusted gross spend figure in 2018/19, it can be seen that the highest spending 15 councils spent about £1.8 billion on people with long-term support needs, on 77,630 people, spending an average of £22,600 per service user. The lowest spending 15 councils spent about £1.1 billion on 84,895 people, which is an average of £12,900. The highest spending 15 councils had an average IMD score of 15.9 and the lowest spending 15 councils an average of 24.7. To spell it out, the highest spending councils spent approaching double the lowest spending – 75% more – on people with equivalent needs.

Characteristics of the councils

One factor at play is population density. A review of the evidence of the cost of providing social care in rural communities (Hindle *et al.*, 2004) concluded there was a cost premium in delivering domiciliary care compared to urban areas. The 15 highest spenders in 2018 included large shire counties such as Hertfordshire, Wiltshire and Surrey, and they served an aggregate population of 6.7 million. The 15 lowest spending councils included smaller urban authorities such as St. Helens, Southend and Salford. The NHS Digital Activity and Finance Report shows the unit costs of home care (Table T49). After adjusting for the impact of regional price differences using the same methodology as above, the unit costs of home care for the highest 15 spenders was £18.40 per hour and for the lowest 15 spenders £15.90, a difference of 15.7%. (Rurality would not be expected to affect residential and nursing provision as there are no travel requirements.)

This cost influences both home care and direct payments expenditure, given that direct payments mostly pay for domiciliary support. These two service areas account for 28% of gross spend nationally on long-term support. 15.7% of 28% means that about 5% of the 75% difference in spend per service user, between the highest and lowest, can be attributed to the rural-urban divide.

The 15 highest spending councils spent £366 per head of population against £314 spent by the 15 lowest spending councils, about 16% more. This points to higher budget levels, more than enough to compensate for the extra costs of rurality. However, by far the largest factor at play in the large spending differences per service user is the number of service users. Dividing the number of service users by the population served (<https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2018-19>) shows the 15 highest spending councils served just 16 people per 1,000 population, while the lowest spending 15 councils served 24.7 per 1,000, 55% more.

This in turn relates to differences in levels of deprivation. The average IMD score for the highest spending 15 councils was 15.9 and for the lowest spending 15 councils it was 24.7. Thus, not only is the scale of inequity very large, it is weighted against the more deprived authorities.

Impact on outcomes

The starkness of this inequity is uncomfortable, but it does provide the opportunity for an acid test of the ‘more money’ argument for social care spending. Do the councils that spend more on service users achieve better outcomes? Against existing measures, the answer seems to be they do not.

The national returns from NHS Digital include surveys of service users about their experience of services (*Measures from Adult Social Care Outcomes Framework*, <https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-outcomes-framework-ascof/upcoming>). A particularly telling one is the extent to which the services they are receiving are improving the person’s quality of life (Indicator 1J). The scale runs from 0 to 1, with the best individual council score in 2017-18 recorded as 0.46 and the lowest as 0.28.

The average score for 1J for both the highest and lowest spending 15 councils was identical at 0.4.

Another measure from the survey is the extent to which people say they are satisfied with the service (Indicator 3A). The 15 highest spending councils averaged 65.5% satisfaction rates and the 15 lowest spending councils achieved 63.9%. Although satisfaction levels are higher for councils who spent more, the difference is not of the order expected as a result of such great differences in spending. It is, at the same time, important to treat satisfaction surveys with caution because of generally low levels of expectations among social care service users.

In a hypothetical situation, if all councils were to spend the same per service user as the 15 highest spenders as shown above, this would cost an extra £8bn, nearly a 50% increase in national funding. However, the evidence above also points to any increase in funding within the current unreformed system as resulting in ‘more of the same’, without any real increase in better outcomes, whether such funding is used to provide more support to existing service users or increases the number of service users.

Why more of the same is not the answer

This is a counterintuitive suggestion. However, there is evidence to support a narrative that seeks to make sense of it.

When need is defined by what people cannot do rather than what they aspire to, the resulting support depresses expectations. Research by Ipsos MORI (Blake *et al.*, 2017) reported a small-scale qualitative study of the impact of unmet need on wellbeing and produced surprising findings.

The report found that getting help with practical daily living tasks of the kind the eligibility process favours was far from being welcomed unreservedly by study respondents. Participants in the study said help could undermine their 'sense of resilience and independence' that Ipsos MORI found was 'associated with positive wellbeing, even in the face of unmet need for support with particular tasks' (Blake *et al.*, 2017, p.6). On the other side of the coin, people (overwhelmingly living alone) placed greater emphasis on the type of social interaction and companionship needs councils tend to say there is no public responsibility to meet under the eligibility process.

Strengths-based practice and Wigan

Building on sector-wide work (Local Government Association, 2014), and with vigorous support by the Social Care Institute for Excellence (<https://www.scie.org.uk/strengths-based-approaches>), the sector has been committed to the promotion of 'strengths-based practice'. This is described as promoting 'individual wellbeing by encouraging independence, self-care, support and learning opportunities for informal carers, before specific service solutions are sourced' (Think Local Act Personal, 2018, p.5). This is seen as the route not only to free the system from its tendency to promote dependence, but to ensure the delivery of good value for money through better demand management.

The present authors have highlighted (Slasberg & Beresford, 2017a) how the promotional claims of success do not stand up to scrutiny, based on evidence in the public domain. While a process of assessment that builds on people's strengths is universally accepted as the right approach, this is not possible within a system that allocates resources using deficits as the currency for decision making, and that is designed to deny the existence of a funding gap.

Nonetheless, promoting strengths-based practice remains sector policy. Wigan Council, perhaps above others, has been seen to champion the approach. It has created the 'Wigan Deal'. The 'Deal' is a whole council movement that originated in adult social care. It sought a radical redefinition of the relationship between state and citizen, reversing the dependency that has developed in the wake of the 1948 welfare state settlement. Wigan was inspired by the work of Hilary Cottam, a social entrepreneur with a background in international banking, whose work has been described in *The Guardian* as capable of 'transforming Britain' (Freedland, 2019). The approach is based on the belief that the welfare state was built for 'a world that no longer exists'. It has created a 'transactional, pass the parcel' bureaucracy. The future lies, it is said, in citizens taking control over their lives, building on their own assets.

The Kings Fund carried out an independent investigation into the 'Deal' (Naylor & Wellings, 2019). It came to a very positive conclusion. It claimed Wigan has shown that achieving 'substantial savings while protecting or improving outcomes' is possible, 'but only if services are genuinely transformed and upfront investment is available to help bring about new ways of working' (Naylor & Wellings, 2019, p.1).

Certainly, Wigan has reduced spending on social care. Using information available from NHS Digital, in 2010/11 (<https://digital.nhs.uk/data-and-information/publications/statistical/personal-social-services-expenditure-and-unit-costs/personal-social-services-expenditure-and-unit-costs-2010-11-final-release>), and therefore taking into account the Council's own money plus the increasingly important cash transfers from the NHS to fund social care, Wigan spent £111.9 million, which is £125.4 million adjusted to 2017/18 prices. In 2017/18, it spent £119.5 million. Thus, Wigan reduced its spending by 4.8% in real terms.

At the same time Wigan was not exceptional during this period of austerity. Although the cut was above average, 57 councils cut deeper.

There has also been a dramatic fall in numbers of people supported during the same period of time. Nationally they have dropped from 1.7million to 860,000, a fall of 49%. For Wigan, the fall was even greater at 54%, from 10,875 to 4,950 (NHS Digital, *op cit.*).

Other authorities have made cuts with a sense of regret, forced upon them by austerity, with sector leaders believing cuts have 'gone too far' (Garrod, 2018). The key question is whether the claim is justified that Wigan has made its reductions through consent and the win-win of building on people's strengths.

The Kings Fund report relies on two sources of evidence for its confidence – qualitative, in the form of what people in Wigan said to the researchers, and quantitative. Both leave much room to question the researchers' conclusion.

What people told the researchers in Wigan

The researchers found a wave of enthusiasm for the 'Deal' amongst staff from top to bottom. This included political leaders of both main parties, senior managers, operational managers and frontline staff. One social care professional told them "It doesn't feel like a job, it feels like a movement" (Naylor & Wellings, 2019, p.26).

The enthusiasm may authentically reflect what current staff have seen and experienced of the 'Deal'. However, the Council's strategy included requiring all staff to reapply for their jobs. Those who succeeded persuaded the Council they supported the 'Deal'. Those who failed were not appointed and given compulsory redundancy. Staff 'positivity' might be a reflection of shared zeal, or a condition of employment.

Staff enthusiasm was not matched by the residents of Wigan whom the researchers spoke to in focus groups. They found predominantly distrust and cynicism, with concern that the 'Deal' was a 'fig leaf for cuts'. Residents 'wanted much greater reassurance that the council and indeed other people in their community are meeting their part of the bargain before committing to making the changes being asked of them' (Naylor & Wellings, 2019, p.72).

Quantitative measures in Wigan

The researchers looked at overall satisfaction levels. They were a little perplexed to find that overall satisfaction levels were only 'around the average'. This led them to wonder if the 'metrics or methodology of the national survey do not capture the kinds of changes that have taken place' (Naylor & Wellings, 2019, p.63).

The researchers overlooked the specific measure discussed above – The extent to which social care services have improved quality of life (NHS Digital, *Adult Social Care Outcomes Framework*, Indicator 1J). If the 'Deal' is achieving what it claims, building on people's strengths to give them the life they want, it would be reasonable to expect Wigan to achieve well above average here. Wigan's score, however, was exactly the same as the national average at 0.4.

They noted that Wigan's service providers had improved their Care Quality Commission rating. However, that has only brought Wigan up to the standard of the national average (Naylor & Wellings, 2019, p.62).

The researchers went on to give pre-eminence to Wigan's good performance in relation to hospital discharge and rate of emergency readmissions to hospital. Efficiency at the health-social care interface is certainly a valued performance measure. However, the researchers do not make clear why they believe this to be a measure of a radical new contract between the council and residents.

The researchers also refer to one of the Deal's objectives being to 'reduce the need for institutionalised care' (Naylor & Wellings, 2019, p.61). In discussion, they refer to the number of people after reablement still 'at home 91 days after discharge from hospital', with proportions 'significantly higher in Wigan than in England as a whole'. This may be another good measure of joint work between health and social care, but it is not evidence of fewer people going into institutional care.

The obvious measure here is the percentage of service users in long-term residential and nursing care. In fact, in 2017/18 in Wigan, 43.8% of older service users were in institutional care, significantly more than the national average of 38.4% (NHS Digital, Finance and Activity Report data on people in residential and nursing care and all receiving long-term support, undated).

The real deal?

The Kings Fund researchers ask: 'Is the Wigan 'Deal' real?' (Naylor & Wellings, 2019, p.59). The evidence does not support their belief that it is. The quantitative evidence points toward Wigan having responded to austerity little differently from other councils, by raising the eligibility threshold and excluding more people.

The quantitative data discussed here resonate more closely with the caution and cynicism of the residents the researchers spoke to than with the optimism of Wigan's staff.

There is no question that greater funding in the short term is required to shore up a faltering social care system. However, this will not of itself create a progressive or sustainable system. The evidence above suggests that whether more money is used to buy more care for those already in the system, or to increase the numbers admitted to the system, the wellbeing of the recipients will not necessarily be improved. Social care, in its current state, by depressing expectations and failing to build on aspirations, is not the good it is assumed to be, but can actually be bad for people. The attempt to impose strengths-based practice on a deficit-led system appears to be the latest of numerous wild goose chases. A consultation document by the British Association of Social Workers (BASW, 2019) on the future of social care sets out a view that to be effective strengths-based practice should be located within person-centred practice. Strengths-based practice located within the eligibility regime is a potentially toxic mix. This might well explain why so much of the success claimed for strengths-based practice by the sector relates to work at the 'front door', prior to people needing council funded support on a continuing basis.

Strategies led from the top by the sector itself have signally failed. The present authors believe it is time to take a lead from service users themselves, and we go on to discuss their ideas.

Ideas from the service user perspective

Of the numerous national strategies over the past 30 years designed to create a person-centred care system that works for the individual, only one can claim evidence that has shown it to be consistently successful – independent living delivered through a direct payment to enable the person to manage their own support system.

The concept of independent living developed in the UK, as in other countries, in the 1970s and 1980s (Beresford, 2016). It arose from within the disabled people's movement. Disabled people rebelled against their patriarchal and institutionalising experience of the system of state funded care. They believed they were capable of living lives greatly more fulfilling, whilst contributing more to society than the system made possible. The 1996 Direct Payments Act gave authority to councils to offer cash rather than services, thus making the idea deliverable.

The problem is that few are able to use this model of service. It requires levels of skill, time, energy, assertiveness and confidence beyond the great majority of people in need of care and support. Despite strong encouragement by successive governments to increase numbers, only some 75,000 service users are estimated to employ their own staff (Skills for Care, 2019). This is 31% of the total of 237,000 direct payment recipients. The 69% majority are using their direct payment simply to pay the invoices of the services they would have received anyway. 75,000 is 9% of the total of 860,000 recipients of social care.

Independent living as a principle

The United Nations' Convention on the Rights of Persons with Disabilities (United Nations, 2019) has created the key to making independent living accessible for all. It has extracted from 'independent living' as a service model a core generic principle that can be applied to all in need of care and support. Article 19 says:

Disabled people should have equal rights to live in the community, with choices equal to others, and be fully included and able to participate in the community.

Article 19 goes on to make clear this should apply in the 'range of in-home, residential and other community support services' (Article 19b). The UN definition of disability includes all forms of impairment and covers all ages; therefore, the 'principle of independent living' can and should be taken to apply to all who need care and support as a result of physical or mental impairment or difficulty, in whatever setting they find themselves.

If the principle of independent living is to become integral to the social care system, the challenge is how to bring it about. The most certain route is to make it a legal right. Although Article 19 speaks of it as a right, the Convention acknowledges it is for each state to decide how the principle should fit within domestic legislation.

Independent living as a right

A number of disabled people's organisations have formed an alliance to promote independent living (Reclaiming Our Futures Alliance, 2019). They have launched a campaign to create a National Independent Living Service. Their 'core demand' is:

A new universal right to independent living, enshrined in law and delivered through a new national independent living service co-created between government and disabled people, funded through general taxation, managed by central government, led by disabled people, and delivered locally in co-production with disabled people.

(Reclaiming Our Futures Alliance, 2019, p.9)

The document notes that the 'right' to independent living has yet to be enshrined in domestic law. The authors note the *Davey v Oxfordshire* case as a landmark in the delivery of the Care Act 2014, which now provides the legislative context for social care in England. The same document quotes from the judgement 'provisions which are aspirational cannot qualify the clear language of primary legislation' (p.9).

The Reclaiming Our Futures Alliance (ROFA) therefore sees the Care Act 2014 as having failed, believing its duty to promote wellbeing to offer 'insufficient protection against retrogression of our rights' (p.9). ROFA sees the solution as new primary legislation. While independent living requires action across a range of public responsibilities, the campaign believes the social care element should be delivered 'through a new national independent living service managed by central government but delivered locally. The service should be funded on the same terms as the NHS – through general taxation and free at the point of delivery' (p.9). Disabled people should 'have a meaningful say at all levels of decision making with a governing body that is made up of a majority of disabled people' (p.13).

A key political challenge

The right to independent living can be understood as having two core elements – the right to ‘needs’ being understood in the context of independent living, and then the right to all the resources required to meet those needs. The second of these creates a significant challenge for the campaign. A right to independent living is incompatible with delivering social care within a budget, however generous.

Needs for social care are unique to the individual. They arise from the complex interplay of a large number of factors, each of which is highly variable – the nature and severity of the impairment, its longevity, the personal resourcefulness of the person, the resourcefulness within their network of support, the resourcefulness of their local community, the accessibility of local services, the physical living accommodation, and so on. Further, the cost of meeting needs can vary enormously.

These realities mean it is not possible to predict the cost of meeting needs for social care in advance, individually or collectively. Social care would have to deliver on an open cheque basis if there were a legal right to all the resource required for independent living. The challenge for the campaign will be that they are seeking a unique position for social care amongst non-financial public services. All others are expected to deliver within a budget, including the NHS. This would move social care from the back of the queue for public funds to the front. Whilst service users and their advocates would like nothing more, it is difficult to envisage the scenario when this will have sufficient support across the community for it to happen.

A right to an assessment of needs for independent living within a budgeted system

By using key provisions in the Care Act that have lain dormant hitherto, and with a change to government policy, Slasberg & Beresford, 2019, argue it will be possible to secure a right for all needs for independent living to be assessed and costed. The key is the failure hitherto of councils to deliver Section 9 of the Care Act as intended. This section requires councils to assess needs for wellbeing without regard to affordability. A recent (September 2019) High Court judgement (<https://www.localgovernmentlawyer.co.uk/housing-law/397-housing-news/42339-judge-rules-against-council-on-meaning-of-needs-for-care-act-assessment>) included the following clarification:

The needs of adults are assessed in accordance with those principles under s.9. Eligible needs are then identified under s.13, by reference to the regulations. A Care and Support Plan then has to be prepared and kept under review. The local authority must then act on the plan in accordance with the duties imposed by s.18, and may provide further assistance under s.19, in ways that it considers effective.

(R (Antoniak) v Westminster City Council [2019] EWHC 3465 (Admin))

The delivery of affordability, necessary to follow the fiduciary duty to spend within budget, can only be attained by limiting needs met under section 18 – the legal duty to meet need – to a safety floor, with quality of life needs met under section 19. It is not unlawful for councils to fail to meet needs under section 19, whereas it is so for needs under section 18.

Adopting the suggested changes will mean the extent to which those needs are then met will be a matter of transparent political priorities and choice. The gap that now exists between needs and resources will be exposed in the form of costed, unmet need.

Table 1 compares such a system of a right to assessment with the current system and with independent living as a right. It compares this in relation to 6 factors key to the management of the tension between needs and resources in delivering independent living:

- ***Needs identified without regard to available resources*** It is axiomatic that even if the extent to which needs for independent living are met is compromised by resources, ‘need’ itself need not, or should not be compromised. The prevailing eligibility system routinely compromises need in order to ensure spend matches budget (Slasberg & Beresford, 2017b).
- ***Person able to define own needs and support requirements, subject only to enabling independent living and in the most cost effective way*** Once the requirement has been removed to control the assessment in order to deliver spending control, councils will be able to make manifest the often repeated clarion call that people are experts in their own needs. The person’s view cannot, however, be a simple wish list. Service users should be required, with support as necessary, to frame their views into a responsible assessment and plan that makes the best, most appropriate, use of all resources to deliver independent living.
- ***Resources allocated to ensure the greatest extent of independent living for the greatest number of people*** Under the eligibility system, service users compete to prove how bad things are, so as to secure support under the concept of ‘greatest need’. If all needs for wellbeing are identified and costed, with the section 18 duty to meet need restricted to a safety floor, councils can make decisions about which needs to meet under section 18 on the basis of the most positive outcomes.
- ***Resources allocated fairly and equitably*** Controlling spending by controlling the flow of needs which there is deemed a legal duty to meet has resulted in gross inequity. This is because ‘need’ is necessarily defined by resources, thus concealing any inequity in resources relative to need being distributed inequitably. If the comparative extent of unmet need is known, it will be possible to redistribute funding in an intelligence led way as appropriate.
- ***Levels of resources for all to have independent living will be known*** The democratic process that determines public spending priorities will, for the first time, have information about the level of funding required to enable all to have an appropriate level of wellbeing, defined as independent living. It will fall to the democratic process to transparently determine the extent to which people are appropriately supported. Advocates for service users will need to be vigilant.
- ***All resources for independent living provided*** It is self-evident that to independent living all the resources are made available to meet all the individual’s needs for support.

The current system fails to score against any of these 6 factors, while independent living as a right scores against all of them. The middle position, a right to needs for independent living within a budgeted system, scores against 5 of the 6. The 5 factors, however, can be expected to deliver the cultural, practice, managerial and political changes that will be required of the system if independent living is to be the driving vision for social care. This will only leave the right to all resources to be secured. This will arguably be more likely once the system is effectively designed to deliver independent living, and the funding implications are better understood.

Table 1. Comparing systems' capacity to deliver independent living (IL).

	CURRENT SYSTEM ↓	RIGHT TO ASSESSMENT OF NEEDS FOR IL ↓	RIGHT TO INDEPENDENT LIVING ↓
THE KEY ELEMENTS OF MANAGING NEEDS AND RESOURCES IN A PERSON CENTRED WAY TO SECURE INDEPENDENT LIVING ↓	State defines 'need' according to the level of funding it is willing to make available	Right to needs for Independent Living identified and costed with extent met a political choice	Right to all the support required for Independent Living
Needs identified without regard to available resources	X	✓	✓
Person able to define own needs and support requirements, subject only to enabling IL and in the most cost effective way	X	✓	✓
Resources allocated to ensure the greatest extent of Independent Living for the greatest number of people	X	✓	✓
Resources allocated fairly and equitably	X	✓	✓
Level of resources for all to have Independent Living is known	X	✓	✓
All resource for Independent Living provided	X	X	✓

General conclusion: toward a transformed and sustainable future

In the wake of the failure of the personal budget strategy to bring about transformative change, sector leaders do not have a strategy to deliver the transformative changes that have been long sought. There is an intellectual vacuum. Independent living is a concept rooted in the experience and thinking of service users. If the right conditions can be found, it can fill the vacuum. It is tried, tested and proven to be successful. Developed into a principle, the UN definition of independent living can and should be applied to all.

The surest way to move for all to experience independent living is to make it a domestic UK legal right. However, the political challenges to achieve that may be too great, at least in the foreseeable future. In the meantime, the legislation, properly applied, has created the conditions for the assessment of needs for independent living to be a legal right, with the extent to which the resources are available to meet them becoming a transparent political responsibility. This will deliver the UN notion of 'progressive realization' of independent living (United Nations, 2017). This acknowledges states will not have all the resources required in place immediately, but they will need to commit to securing them over time. 'The immediate obligation' is to 'design and adopt concrete strategies' which set states on the road (UN, 2017, para 39). Establishing the legal right for all needs for independent living to be acknowledged and costed will require the transformation of what is currently a largely administrative service that distributes whatever resource is available, against arcane criteria. The transformation would be to a service driven by a vision of how life should be for older and disabled people. This would be a stepping-stone to independent living as of right. It might well be an essential stepping-stone, without which the ultimate vision may never be achieved.

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Notes on Contributors

Colin Slasberg is a qualified social worker, worked in local authorities in children's services for the first part of his career and in adults' services for the second part. Subsequently, he has undertaken analysis and written on policy and its implications, in relation especially to adults and personalisation.

Peter Beresford, OBE, is Professor of Citizen Participation at Essex University and Emeritus Professor of Social Policy at Brunel University. He is also Co-Chair of *Shaping Our Lives*, a national service user organisation. He has written on social policy in the UK and internationally, recently most extensively in *All Our Welfare: Towards Participatory Social Policy* (2016).

Correspondence

E: colin.slasberg@gmail.com