Living well with long-term conditions

Twelve propositions for social care

Discussion paper for Long Term Conditions and Social Care Dialogue Event
Prepared by Jim McCormick
Preface

More than 2 million Scots of all ages live with a long-term condition. LTCAS brings together a wide range of charities which exist to support people with long-term conditions, their carers and advocates. Leading clinical and social research takes place in Scotland into some conditions, while the National Dementia Strategy and the Self-Management Fund are vital signs of progress. The NHS is better at understanding and responding to complex conditions now than a decade ago. But what about our everyday lives, when some need low-level personal support to remain independent while others need specialist know-how in the community to live as well as possible? How does social care contribute? And what needs to change?

To help address these questions, a new programme on social care and long-term conditions has been established with the active support of various LTCAS members. Special thanks are expressed to those who submitted case study examples; to Shelley Gray, Justine Duncan and Ruth Michie at LTCAS; and to interview participants: Jim Elder-Woodward (Independent Living in Scotland), Henry Simmons (Alzheimer Scotland), Sarah Cockburn (IRISS), Annie Gunner-Logan (CCPS), Maddy Halliday (Stroke Association Scotland), Tanith Muller (Parkinsons UK), Ranald Mair & Gloria Mcloughlin (Scottish Care) and Lynn Williams (Princess Royal Trust for Carers).

This discussion paper sets out a map of the main issues identified in round-table dialogue, information interviews and a review of published evidence. These are grouped into twelve propositions on how social care can contribute more towards people’s wellbeing – whatever their condition type or age and wherever they live.

1. First, recognise the context

We know that more Scots are living with long-term conditions, living for longer and often living alone. Long-term conditions can be grouped – very broadly – into those which are:

- long term but often stable (e.g. life after a stroke)
- long term but with prospect of recovery or fluctuation (e.g. mental health problems)
- long term and progressive (e.g. Parkinsons and dementia)
- linked (e.g. pathway from high blood pressure/cholesterol/obesity to some types of diabetes, stroke and vascular dementia)
- multiple (e.g. physical impairment following stroke; learning disability plus dementia).

Almost half (46 per cent) of households with care needs contain only one adult. Many will be supported by a family member or friend. The latest Scottish Household Survey
shows three times as many adults providing unpaid care to someone who doesn’t live with them as do within the home. But many others will have their care needs only partially met by formal and informal support.

This picture of an ageing population with growing care needs is familiar. So too are the constraints imposed by the state of the public finances. Scotland’s Chief Economist expects the decline in public spending to last at least 15 years. The equation goes like this: getting better outcomes from smaller budgets can only really be done by reducing need – or taking demand out of the system where possible.

In this context, it seems apparent that we are in the midst of an important conceptual shift – spanning self-management, personalisation and preventative spending. The Christie and Beveridge Commissions go with the grain of what’s already underway. Equally apparent, though, is how a broad consensus in favour of this shift runs way ahead of investment to make it happen. The Change Fund as part of Reshaping Care for Older People is an important mark of intent. The forthcoming Self-Directed Support Bill offers the clearest chance yet for Scotland to close the gap between promise and practice. But the principles of user control, voice and choice – and simply “being listened to and treated as capable adults” as carers’ groups put it – need to become the default mode for social care, not only expressed within the limits of a single programme or legislative plan.

Interviews conducted to inform this paper point to a very clear need for more flexible and responsive use of all care resources. We need to be able to “reach for the volume control not just the on-off switch” in assessing what we’re each capable of, what our needs are and how to adapt our response over time. Despite progress led especially by the Independent Living movement, we’re still a long way from ensuring Scots with long-term conditions get the right kind of support to stay well for as long as possible. Some feel like they are the ‘poor relations’ in health as well as after-care:

“There is nothing much in the community as after care for people who have had a stroke. People who have had a heart attack get after care so I take it we are the poor relation and that the NHS isn’t caring about us” (Stroke survivor, women in her mid-50s).

2. Adapt to emerging needs

One ‘vital sign’ of a better social care system will be its ability to adapt to emerging needs, including needs that may be long-established but neglected. It’s striking, for example, that the experiences of children and young people with long-term conditions, and parent carers, seem absent from our deliberations. There may be carefully designed clinical pathways in the NHS for children with complex health conditions, but what about families facing the most intensive, lifelong care responsibilities? How good is the support they can count on for everyday living? And what about transitions into the world of adult social care?

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1 L Bunt and M Harris with R Puttick (2010) Radical Scotland: Confronting the challenges facing Scotland’s public services, London: NESTA
2 Case study provided by Stroke Association Scotland
Another challenge arises in the emotional and psychological support needs of people with long-term conditions and their carers. These may arise in adjusting to a new impairment with little prospect of recovery, following some types of stroke for example\(^3\), or living with a degenerative illness. Depression may occur through loss of identity and independence or be linked to organic brain impairment. Older people doing most of the care for their spouse or grown-up children are much more likely to have poorer physical and mental health themselves. Support to relieve chronic stress on carers can improve their own quality of life and their ability to carry on giving care for longer.

In addition, the growing risk of loneliness might be regarded as a long-term condition in its own right. Living alone but isolated from family and friendship support can’t be regarded as independent living. There’s growing evidence that social isolation in later life isn’t just a risk factor for depression but dangerous for physical health and mobility\(^4\). Survey evidence suggests that older people are increasingly living well. Self-rated poor health grows with age, but more than 70 per cent of Scots aged 75+ still rate their health as at least good\(^5\). However, a turning point occurs for some in their 80s when a marked increase in mental ill-health emerges (based on survey evidence from England)\(^6\).

**Mental ill health by age and sex (% scoring 4+ on GHQ12, England 2004-06)**

![Mental Health by Age and Sex](image)

Depression at this stage is under-diagnosed in part because it is often viewed as a ‘natural’ or inevitable part of getting older. In fact, there are significant differences in personal resilience following bereavement for example and in quality of life among people living with dementia.

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4 See for example JRF’s Neighbourhood approaches to loneliness programme [www.jrf.org.uk/work/workarea/neighbourhood-approaches-loneliness](http://www.jrf.org.uk/work/workarea/neighbourhood-approaches-loneliness) and the Campaign to end loneliness: connections in older age [http://campaigntoendloneliness.org](http://campaigntoendloneliness.org)


In the community, people with long-term conditions of all ages value the mutual support that comes from being part of a peer group/member of a club or taking part in activities where they can contribute as well as get support:

“I am retired from work due to ill health but have various hobbies including cooking and photography. I am also an active member of the committees for two clubs. I have reduced income but also reduced expenditure as a result of not working. I play an active part in our local community and see myself as outgoing, happy, useful and helpful to others” (Stroke survivor, man in his early 60s).

Reciprocity is an under-valued element of care. Volunteering support for housebound people using telephone networks demonstrates that people who receive social care can also provide support to others. And while supporting people’s ability to stay part of social networks in the community is the best starting point of all, similar expectations should apply to other places where people are cared for including long-stay hospital wards and care homes. Recovery and rehabilitation is likely to be aided by stimulation. Too often, people experience stifling boredom, a lack of things to do, people to talk to and opportunities to be mobile. A commitment to involve volunteer befrienders and a duty to commission learning and leisure activities should be considered as an essential part of their role.

3. Start with Rights

Past efforts to improve public policy – in education, health, welfare – have appealed to the enlightenment of policy-makers, the goodwill of practitioners, the return-on-investment case to budget-holders and, at times, to public outrage at the position of vulnerable people. These are legitimate elements of any push for reform. But they are best viewed through the sharply-focused lens of citizenship. Taking a rights-based approach to social care doesn’t get us off the hook of making hard choices on resource allocation, but it does offer more fertile ground in which to embed progress. When the Joseph Rowntree Foundation began to fund its biggest current programme A Better Life for older people with high support needs, it quickly concluded that the standard currency of the debate – concepts like dignity and respect – wasn’t tough enough. These are valuable qualities to be promoted, but they involve relying on others to bestow them. So, we take our chances that a skilled social work manager or homecare worker will have the empathy and time to demonstrate them. But what about when this fails? A rights-based approach can help to clarify expectations of fair, consistent and respectful experiences and of redress when standards fall lower than this.

Progress to embed human rights in law has been reflected to varying levels in social care – for example, the 14 Rights to Independent Living used by Inclusion Scotland, application of the United Nations PANEL approach to human rights for people with dementia and a push for the right to self-assessment in community care, as well as

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7 Case study provided by Stroke Association Scotland
9 JRF programme A Better Life www.jrf.org.uk/work/workarea/better-life
work around human rights in healthcare as well as compassionate care in the NHS. This case study from Independent Living in Scotland offers a personal experience of care assessment:

“The whole [assessment] process and my own principles confirmed my belief that community care assessments were too focused on feeding, cleaning and toileting people and that they often failed to account for people’s social needs, to take a holistic approach…Community care for me…was about giving people the resources to lead an independent, flexible, full lifestyle and this is why I believe firmly that the individual must have the right to self assess. I think to understand the importance of community care we must appreciate this: it is not a service that should exist to allow people to exist, it is one that should exist to allow people to live.”

Before long, the stuff of rights to be voice, choice, participation and so on bump up against rationing of care budgets. In many parts of Scotland, a ratchet effect is underway which leads local authorities to raise the threshold for basic homecare support (see box). In order to protect care packages for those with higher support needs, low-level/preventative support is being reduced or at risk of being withdrawn.

### Rationing in social care

- “Care stopped with no warning and still no explanation”
- “Care stopped on review after made complaint about home help and social worker”.
- “Had to wait 18 months for Direct Payments to start.”
- “My family take care of me. Medical personnel have no conception of how ill this disease makes me feel…and care staff have a disturbing apathy towards it. We’ll go it alone as a family for as long as possible.”
- “Short breaks service gives me 4 hours per week. This has been under review for about 15 months as the council want to halve the service because of cost involved. No decision has been made...The stress of not knowing the outcome is extremely wearing.”

More starkly, the case of *R (McDonald) v LB Kensington and Chelsea* reveals how a stroke survivor was denied night-time support to go to the toilet by one of the most affluent councils in the UK. Taking the case to court, her appeal was lost on the grounds that providing continence pads for overnight use was sufficient to meet her right.

Contrast this with the successful legal challenge by prisoners against slopping out. Their rights to dignity and hygiene were enforced when Justice Ministers and Prison Governors had failed, suggesting rights are not divisible according to where we happen to live. With this test case established, how will Scottish councils respond? And how can we embed citizenship in good decision-making – by negotiation and with consent – rather than having to resort to the law to secure our rights?

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11 Case study of Pam (2009) submitted by Independent Living in Scotland
12 Examples from people with severe ME and their carers, submitted by the 25% ME Group
4. Decide what kind of prevention we are seeking

Prevention – and specifically preventative spending – has quickly become as a guiding principle in discussions of Scottish policy. Encouraged by the Beveridge and Christie Commissions and the Finance Committee’s Inquiry at Holyrood, prevention may be written in as a permanent strand in the Scottish Government’s Economic Strategy. This is driven by the projected 11% cut in public spending by 2014-15, but it would be a mistake to see prevention as just about cost-cutting. Applied with care, it should contribute to better outcomes – for example, by ensuring people receive support at the right time, when they benefit most, in order to recover or stay well for longer. However, we need to ‘unpack’ the concept of prevention further if it’s to be useful in reforming social care:

- From a whole population or public health perspective cholesterol and obesity as risk factors in some cases of stroke, diabetes and vascular dementia.

- On an everyday basis, boosting the protective factors that enable us to live with long-term conditions also feeds into future demand: support to widen and maintain social networks, exercise and access to “that bit of help” with gardening, home repairs, housework. We know a lot about the role of friendship ties and leisure interests in enabling people with dementia to stay active in the early stages of the disease. Alzheimer Scotland propose a three-person team made up of a CPN, social worker and link worker supporting around 150 people with dementia in the early period following diagnosis. The team would be “skilled in both dementia practice and person-centred approaches...planning exceptionally high quality and creative personal support solutions for each person”\(^{14}\).

- In turn, these can help to delay the need for unwanted higher-cost care. Prevention might mean deferred use rather than never having to use day-care, go into hospital or residential care while the extent and cost of service use can also be reduced in combination with informal care where it’s sustainable. Preventing carers experiencing crisis is an integral part of the agenda. For example, support for the family of stroke patients is linked with a reduction in depression of up to 27% and a reduced need for physiotherapy\(^{15}\).

- And where people are already part of the social care system, secondary prevention can stabilise or reduce demand over time, for example by cutting the risk of another stroke and through targeted support for re-ablement (see box).

<table>
<thead>
<tr>
<th>Homecare re-ablement</th>
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<td>Homecare re-ablement provides a relatively new focus on helping people to recover their ability to take care of themselves on a daily basis following a period of illness or incapacity. Typically, a six-week period of support is provided to help with washing,</td>
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\(^{14}\) H. Simmons (2011) Speech to Glasgow Dementia Convention, March.  
\(^{15}\) Princess Royal Trust for Carers and Crossroads Care (2011) Supporting Carers: The case for change
dressing, cooking and toileting. At this point, a fresh assessment of capacity and need takes place. The evaluation evidence from Edinburgh (after 12 weeks)\textsuperscript{16} and five English local authorities\textsuperscript{17} (after 1 year) is broadly positive. Re-ablement led to a 60% decrease in the cost of care services used over 12 months compared with conventional home care users. These lower costs were offset by the higher cost of the re-ablement itself, so net savings were marginal. However, quality of life measures were higher than in the control group. Among the issues still to be addressed:

- We don’t know how long the benefits may last beyond 12 months
- Could re-ablement approaches be adapted to benefit a range of condition types: e.g. regaining functional ability with a stable condition versus managing a degenerative condition?
- How far could it be used in other places, e.g. extra-care housing and short-term use of care homes?

5. Apply personalisation with a purpose

Personalisation is regarded by many as an expression of rights in social care. The forthcoming Self-Directed Support (SDS) Bill thus takes on even greater significance as one means by which the right to personalised support will be secured in Scotland. What kind of reform is called for, and to what end? Participants in this project use different images. Some see SDS as ‘a battering ram’ into a system that is stuck. Others see it as ‘a scalpel’ to be used with skill or use the metaphor of acupuncture, in order to remove blockages and get the energy flowing better. Either way, SDS needs to be part of a profound shift in culture, assumptions and behaviour on the part of many service commissioners and providers in how capacity/need is defined, how support is sourced and how services involve citizens. Some see individual budgets including Direct Payments as a positive disruption to the social care market. By devolving budgets to people with long-term conditions and carers to make decisions, new patterns of demand and supply will emerge. Block contracting by volume would then be eroded and the sense of empowerment or user control increase. The cost/benefit balance for individual budgets is touched upon later (see proposition 8).

Case study evidence from people with debilitating conditions using Direct Payments varies. Some feel in control of their lives again as a result of the greater flexibility in care achieved:

“When I had agency care, I was miserable. I saw so many different carers, each one of whom I had to teach how to look after me, and I had little control over when they came and what they did. Now I know exactly who is coming when, and I am in control over what they do and when. I am happier to have the responsibility of managing a group of carers, to cover all my hours, and who I have chosen by interview...I am so fortunate to have found caring, loyal and flexible staff. New carers learn from each other, and all have absorbed a lot of...

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\textsuperscript{16} IRISS (2010) ‘Effectiveness of re-ablement services’ Insights No.3 \url{www.iriss.org.uk}
information about my condition, and its effects on me. This system works for me\textsuperscript{18}.

Alzheimer Scotland has researched the experiences of a group of people with dementia and their carers using Direct Payments, identifying the potential of this option as well as the barriers\textsuperscript{19}.

However, some caution was also expressed. Low take-up of Direct Payments reflects awareness but also examples of trying to apply and giving up. One woman contrasted her positive experience while living in South-East England with the hurdles encountered when she moved to Scotland:

“Even the person at the care agency was absolutely convinced that [the Council] were trying to stop people because it was so complicated – it wasn’t just me – normal, well people looked at it and blanched – “I couldn’t do that.” How anyone could think that anyone who is ill enough to need care could do that is beyond me... I was presented with awful material that reflected a horrible attitude – prospective applicants are treated like criminals as the attitude seems to be that you are going to try to rip them off. The amount of feedback required was worse than doing a tax return\textsuperscript{20}.”

In terms of recovery and preventing further ill health:

“If [care] services had been in place, my health would have improved. Now I need more help rather than less. What time and energy I’ve had has been spent on trying to survive and get the basic care. I wanted to be putting my energy into getting better\textsuperscript{21}.

We know that awareness and take-up of Direct Payments is lowest of all among frail, isolated people including older people who lack informal support. People who live alone, are very ill or tired may lack the everyday back-up that others can count on to make the process work:

“In theory direct payments is a brilliant idea [but]...it turns ill people into employers. Keeping up with the administration side is very tiring. More of a problem is the stress associated with all aspects of recruiting and supervising a carer in your house. If you are only having a few hours each day it is very difficult attracting applicants. I have had two amazing personal assistants (one was a friend before) and three who were really awful...actually disabling me. They made my life very, very unpleasant. I lost a lot of sleep, so became even weaker, less able to do things and depressed. Getting rid of them was extremely stressful. I am now back to just having agency care. At least if they send someone I don’t like, I can refuse to have them again!”\textsuperscript{22}

\textsuperscript{18}‘My experience of Direct Payments’ by Lyn, ME Quarterly
\textsuperscript{19}Alzheimer Scotland (2011) See Let’s get personal - personalisation and dementia and Taking Charge - a short guide to self-directed support for people with dementia and their carers.
\textsuperscript{20}Direct Payments case study submitted by The 25\% ME Group
\textsuperscript{21}Ibid.
\textsuperscript{22}‘My experience of Direct Payments’ by Wendy, ME Quarterly.
We also know that even when Direct Payments work well, people can still end up with lousy experiences if they need to go into hospital. So there are limits to individual budgets in achieving reform. The answer isn’t likely to be individual budgets for all. Instead, personalisation needs to be framed as widely as possible. Self-directed support must also push ahead with cultural change in how mainstream care services people with long-term conditions. Where people lack the capacity to speak up for themselves, or where fear or the ‘gratitude barrier’ holds them back, independent advocacy support can assist people to achieve personalised care.

6. Balance generic and specific approaches

One tension running through social care is how far generic approaches can be expected to work for people with different conditions types – and for that matter, different experiences of the same conditions. Good generic approaches like person-centred planning will apply to all long-term conditions and generic advocacy networks can work with condition specialists (both professionals and peers) to extend their support to people who might otherwise not be able to access it. Examples include the Stroke Association’s partnership with independent advocacy groups and local Carer Centres becoming better able to support the diverse circumstances of carers. In this way, generic capacity can blend with specialist know-how without duplicating effort.

One motivation for this project is the view that the NHS tends to see only the clinical dimension while, for the bulk of service users, social care tends to focus on basic ‘time and task’ activity to enable people to function. Both of these have an important place in the mix (see proposition 7), although home-care visits of only 15 minutes are likely to be inadequate in many cases. Neither is adequately skilled in addressing the changing emotional and psychological side of the care equation. More insight within the NHS on what it takes to live well, and within social care on common features of specific conditions, would help. Examples include:

- Risks to personal safety for people with Alzheimer’s as their condition progresses;
- Undiagnosed depression among Stroke survivors and their carers related to identity shift and sudden changes in roles;
- Unpredictable medication needs among people with Parkinson’s disease.

These circumstances are not unique to each condition, but they illustrate the need for social care providers to understand and address possible consequences. Social care staff may be unable to give medication if someone can’t self-medicate due to cognitive impairment or reduced dexterity and medicines aren’t pre-packed or are needed on a responsive basis (e.g. due to increased pain). Home carers may be well-placed to spot the difference between having depression and just a bad day, but may not feel skilled or authorised to act. Condition charities take different approaches to improving specialist knowledge in the community as well as in hospitals and care homes, including specialist nursing staff, developing training guidance in partnership with NHS NES, awareness-raising for Social Work managers and homecare staff. There’s a strong case to develop care qualifications to enable practitioners to address more complex circumstances. However this is done, we need to invest in self-management, peer support and training for carers at the same time.
7. Create a system for wellbeing - not just better social care services

Putting these elements together – rights, personalisation, prevention – we have a picture emerging that adds up to more than social care reform. ‘Social care’ will probably keep an in-built default to the ways things have usually been done for most service users. Even ‘service users’ becomes a tricky concept, implying that we make use of something that exists ‘over there’, that’s already prepared. When we’re getting better at defining outcomes, it might be better to set our sights on the contribution that social care ought to make to our lives.

The approach suggested is:

- we apply ourselves to putting these attractive elements into practice, consistently well;
- we add in a more sophisticated approach to health care which is able to address complex and multiple conditions in the round;
- we recognise that time and task activity is often necessary to enable people to function but not sufficient to help them live well;
- we strive to go beyond the limits of ‘social versus medical models’, recognising the inherent dangers of vacating the pitch when it comes to how the NHS also needs to be personalised for people with long-term conditions and impairments;
- we share the common goal of living well for as long as possible with long-term conditions;
- and we create a system for wellbeing to express this goal;
- which spans the dividing lines between age groups, physical and learning disabilities, physical and mental health conditions;
- with social care reforms being one significant contributor to a system for wellbeing.

This points to an understanding terms like ‘independent living’ and ‘empowerment’ not as ends in themselves, but as rights through which we manage to live well with long-term conditions whether the pathway we are on involves recovery, stability, degenerative or terminal illness. Thus, the policy goal of “keeping people in their own homes” which could be regarded as a synonym for independent living might in some cases be shoring up loneliness or increasing the stress upon carers. When we check against the goal of wellbeing, we’re prompted to look at what kind of support could enable someone to get out of the house safely, be involved in the community or get respite when it would seem easier in the current system, at some level, not to. Defining our goal as a system for wellbeing is not about semantics or avoiding hard choices. Nor is it in any way a new idea. Instead it requires us to change what we invest in and how we judge effectiveness; the mix of people involved and the relationships between them; and the governance system that underpins the shift. We consider these elements next.

8. Use money for change

To begin with, money needs to follow the best of the evaluation evidence available. After more than a decade of policy-makers signing up to the mantra of ‘what works’, it’s striking how the evidence rarely plays more than a minor role in long-term change. Of course, evidence isn’t all that counts. It’s not value-neutral, it’s never definitive and there are usually risks in translating findings from pilots or test cases into mainstream
practice. But it ought to count for more. Many large-scale policy evaluations come from England and it’s understandable – if often mistaken – to assume a different policy environment means the evidence is not directly relevant. Usually, there are enough good insights to enable Scotland to adapt the evidence when appropriate. Even where we do have robust, home-grown evidence, we may be unable to track whether this has influenced investment decisions in local authorities.\(^{23}\)

Evaluations of social care change tend to look at both the overall costs/savings and the benefits in psychological wellbeing, capability, satisfaction and feeling in control of daily life. Budget savings can be found across various elements of a programme even if total net savings are relatively small or appear over a period of years. More significant savings include the social return on investment attributed to greater capacity in Carers Centres\(^ {24}\) and the early planning approach advocated by Alzheimer Scotland soon after dementia is diagnosed\(^ {25}\). It is estimated that a delay in using long term care of four weeks would fund post diagnostic support for a year.

In many cases, the quality of life benefits are significantly higher than any net savings, so that the chances of deferring or avoiding high-cost care later (i.e. outwith the scope of most evaluations) are increased. The limited evaluation evidence we have to date on individual budgets in England suggests that overall service costs are only slightly lower for budget-holders compared with others using traditional care services, but on a cost-effectiveness basis many outcomes are better. The table (over) gives a brief summary of evaluation findings on homecare re-ablement, self-assessment and individual budgets.\(^ {26}\)

Other relevant evidence includes:

- A Finnish approach to dementia family care coordination: providing intensive community-based support delayed early admission to residential care. After two years, the likelihood of being in residential care was the same as for the control group. The longer-term outcome does not diminish the savings and benefits achieved in the first two years.

- A large-scale telecare approach in two English counties (‘Safe at Home’): reduced stress on carers, helping 60% of people with dementia to remain at home after 2 years compared with 25% in the control group.\(^ {28}\)

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\(^ {23}\) For example the Working for Families programme: see findings on the implications for policy and practice by Ron McQuaid and colleagues at Napier University: [www.jrf.org.uk/publications/how-parents-escape-recurrent-poverty](http://www.jrf.org.uk/publications/how-parents-escape-recurrent-poverty)


\(^ {25}\) See for example Henry Simmons (2001) speech to Glasgow Dementia Convention, March


- A community network of mental well-being cafes and related activities for older people in Bradford (‘Health in Mind’): a ten-year programme including specialist support for people with dementia and for Asian elders. After five years, the benefits outweighed the costs with substantial savings projected after ten years.\(^{29}\)

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<thead>
<tr>
<th>Type of support</th>
<th>Evaluation findings</th>
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<tr>
<td>Self-assessment</td>
<td>Self-assessment pilot for older people with low-level needs: this approach was 70% cheaper than a care manager assessment, while satisfaction levels and the cost of services used were similar.</td>
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<tr>
<td>Individual Budgets</td>
<td>IBs found to be most effective for psychological well-being and social care outcomes for mental health service users, then for younger people with physical disabilities and least so for older people. Overall costs are only slightly lower than for the comparison (non-IB) group, but feeling in control of daily life was significantly higher.</td>
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What might we conclude from this brief look at evaluation findings? First, we need to take care not to extend the evidence too far. For example, the self-assessment example in the table showed significant costs savings and take-up of a wider range of light-touch support services at an early stage - but only for older people with low-level needs. It would be mistaken, to say the least, to move all older people inquiring about social care over to self-assessment and expect a 70% cut in assessment costs. Second, we need to be patient and measure impact over time. An early evaluation of Bradford’s ‘Health in Mind’ programme would have looked much less promising than the picture by the fifth year.

If we have decent evidence of approaches that deliver better outcomes and either cost less or are revenue-neutral, why aren’t they the norm? In part, this must reflect the in-built tendency for systems to replicate themselves. In Scotland, policy-makers are acutely aware of the costs locked into default use of hospital for emergency admissions.

among the over-70s. The Change Fund to reshape older people’s care is a brave attempt to provide bridging finance for community alternatives. An indication of whether the tide is turning will be when it’s easier to get rapid ‘step-up’ social care and essential medical support in the community (e.g. hydration) overnight and on weekends than to get a hospital bed; and easier for someone with dementia to access a more flexible support package rather than taking the ‘care escalator’ from a few hours of home-care straight into residential care.

In the meantime, a consistent message from respondents to the project was: beware competition for less money between people with different levels of need (low-moderate versus acute); condition types; and age groups. While there is strong support for reducing demand through the approaches discussed here, there is also concern about the short-term threats: “It’s going to get rough out there.”

Faced with the current content, it seems clear that we should broaden the lens to consider the full set of resources – money and people (proposition 9). More investment will be needed beyond the Change Fund to ensure low-level support is not neglected. Perhaps ambitious thinking on social impact bonds will deliver for social care in future. But before then, alternative priorities could be set within the next Scottish spending review to ensure a bigger budget for prevention.

9. Involve people for change

Where should responsibility for change be located? We can take action at all levels to achieve better outcomes. Where appropriate, this begins with self-management support for people with long-term conditions. The Self-Management Fund run by LTCAS makes clear that self-management doesn’t mean individuals are on their own, but that their everyday expertise in living with a condition is the best starting point. Group-based approaches to self-management may work best for people with communication and sensory impairments, such as the Lifestyle Management Programme developed by The Thistle Foundation to achieve “coping, control and confidence”. There’s good evidence, too, that practical training for carers can relieve stress and make care-giving more sustainable. So, combining the themes of prevention and rights, we might regard support for self-management and carers as the absolute essentials of the system.

Peer networks – both face-to-face and on-line – can provide a different quality of support to complement other services. There are good examples of condition specialists working with independent advocacy networks (e.g. Stroke Association) and Carers Centres supporting parents of children with autism to improve support where it’s been lacking.

For a small input of encouragement and co-ordination, peer support can deliver significant benefits as parent carers across Scotland have found by joining a Facebook support group to exchange know-how on helping their families cope better with

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30 Evaluation of the Partnership for Older People’s Projects (POPP) in England showed positive cost-benefit returns on local support for prevention, but the savings remain with the NHS. See McCormick et al (2009) ibid. Also see IRISS (2010) ‘Southwark Hospital Discharge’ Money Matters case study 8 www.iriss.org.uk
31 www.thistle.org.uk/our-services/health-wellbeing/lifestyle-management
autism. By gaining practical knowledge from other parents, one woman posted: “I feel like I’ve got my son back.”

We have referred previously to various key-worker models being supported by condition charities as the community ‘anchor point’ to ensure people with long-term conditions have local access to the support needed. Key-workers may be specialist or more generic advisers. Charities can learn a lot from each other about effective approaches. These include the Stroke Association’s Local Life After Stroke services, Alzheimer Scotland’s post-diagnosis support teams, outreach work by Carers Centres with condition charities and Parkinsons UK community nurses. The striking feature from these examples is the need to extend successful approaches further: they are not searching for a model that works, but resources to ensure more of their target groups benefit from them.

This leads us to the social care workforce which delivers home-care, residential care and is involved in planning care in hospitals, as well as the growing network of Personal Assistants employed using individual budgets. They span public, voluntary and independent sectors and so face different environments in terms of pay, conditions, training, progression and relationships with the people they support. Whatever type of integration we opt for, and whatever variations in the balance of care exist across Scotland, we should ask a common set of questions:

- Does the provision of social care express the values and ethics contained in the earlier discussion of rights, personalisation and prevention?
- Are we developing the skills of everyday co-production between the workforce, people with long-term conditions and their carers?
- How good is our workforce training and development at encouraging reflective practice, empathy and problem-solving?

Structural reform should be seen as a possible means to an end rather than a solution in its own right. Whether transferring the front-line social care workforce from local government to the NHS is good for people with long-term conditions depends on the type of culture change it is intended to prompt. For too long, it can be argued, Scottish policy-makers have focused on tinkering with the remit and geographical scope of organisations rather than looking at the culture and behaviour within them. So, within the current system it is possible to have significant variations in the quality of care provided by the same workforce, in the same neighbourhood or the same care home, and between personal assistants. It doesn’t just reflect management and leadership roles, critical though these are, but the personal qualities people bring to work:

- One example involves a cleaner who became the home-help to an older woman following a stroke and later became her main carer. More important than qualifications or experience of working for a care agency was the dedication and trustworthiness demonstrated. In this case, a lot of

32 Example submitted by the Princess Royal Trust for Carers
33 www.stroke.org.uk/in_your_area/scotland/local_life_after_stroke_services/index.html
upheaval and cost were avoided by taking an informal, self-directed approach to care\(^{34}\).

- From personal experience, home-carers may respond differently in the homes of older people living alone. One carer stayed up overnight with a bereaved woman whose family lived too far away, while another spent most of a visit to a disabled woman with dementia in a different room, smoking and catching up with personal phone calls.

- Managers and the workforce in three Scottish care homes were able to transform the quality of night-time care by making simple, low-cost changes to the living environment based on feedback from a team of researchers working alongside them on the night-shift\(^{35}\). The changes didn’t come about due to a new policy, inspection or regulation but a commitment to find practical solutions to long-running problems.

Finally, there’s the issue of the wider population. Between the family, the state and the services it commissions from other sectors, what’s the community stake in social care?\(^{36}\) Such questions start to bump up against the Prime Minister’s Big Society ideal. In Scotland, this is usually given short shrift for two reasons: either we already have a big society thanks to the commitment of volunteers in every community, school, church and workplace; or because politicians stand charged of hypocrisy – voluntary sector services would be spared the worst of the spending cuts if they truly believed in a big society. And yet, this can’t be enough as a response to David Cameron. There are genuine questions to be addressed here:

- Will self-management plus prevention plus personalisation be enough to deliver better outcomes with less money?
- How far is it desirable or practical to increase the social care workforce to meet future need?
- Is there scope to adapt practice from other countries which recognises the contribution of volunteers/befrienders, for example the time-banking currency established 20 years ago in Japan (see box)?

\(^{34}\) Case study submitted by Linda Jane McLean (2010)

\(^{35}\) Diana Kerr, Heather Wilkinson and Colm Cunningham (2009) Supporting older people in care homes at night, York: JRF

www.jrf.org.uk/publications/supporting-older-people-care-homes-night

\(^{36}\) David Brindle (2008) Care and support - a community responsibility? York: JRF

Timebank for community care (Japan)

- Japan has a significantly older population structure, with the care system placing strain on public finances.
- But it also has the highest levels of life satisfaction among the over-65s in OECD.
- Japan introduced a ‘care currency’ (Hureai Kippu) in 1991 exchanged through a timebank for older people’s care.
- Volunteers earn credits which can be transferred to provide care for older relatives or banked to provide their own care in future. It helps ensure care is available for families living far apart.
- This example shows how one country has responded to the pressure of providing good enough social care by focusing on everyday relationships. Rather than adding more complex and costly services through the state, Japan has established an innovative means of contribution and exchange. This has helped to strengthen social ties and encourage communities to play more of a role, knowing that their efforts are recognised and credited.
- It could provide a foundation for anticipatory care (low-level focus on prevention) elsewhere.

10. Shape governance for change

Respondents to the project believe the Scottish Government has a very significant role in shaping the future of social care. Interviewed shortly after the Dilnott Commission reported, the UK Government’s decisions on paying for long-term care and on welfare reform are seen as equally important, though respondents were not yet clear how the consequences would affect policy choices in Scotland. For now, the main concerns relate to the changing local governance landscape.

Frustrations were expressed about the way in which the Concordat may be driving major care inequalities due to the ratchet/ration effects noted previously. Since care packages apply only to the local authority making the assessment, a working person with high support needs is likely to feel unable to move to another area in case their support is put at risk. Concerns are raised as well at the apparent contrast in standards of accountability applying to local government compared with the third sector. Meanwhile, the NHS is managed more directly and tightly by the Scottish Government than councils. Local democracy is valued, but has its limits. Ring-fencing of budgets has been reduced substantially but not removed completely – and the rationale for deciding when it should apply isn’t clear. So, most respondents would welcome an offer of ‘help and hassle’ from the Scottish Government in response to local authorities which take a short-term approach to cutting costs and raising eligibility thresholds, and dialogue on:

- Which differences in social care assessment, eligibility and service charging are regarded as just variations or unacceptable inequalities?
- How much variation is too much?

• How should we act if voluntary approaches (e.g. sharing good practice, user voice) are inadequate?

Let’s return briefly to the Change Fund for older people’s care. It is regarded widely as the right approach in principle. In fact, top-slicing of resources to demonstrate local care alternatives is seen as a useful model to apply in other cases. But some early have been less promising. There’s concern that some local plans have only a weak connection to evaluation evidence or to national commitments on long-term conditions, dementia, stroke and so on, prompting respondents to ask: “if my local authority and Health Board still don’t know what their priorities should be for older people, why are they in the lead on the Change Fund?”

As the Change Fund progresses, a tight focus on better outcomes is needed and the various pathways towards achieving them – or theories of change – should be explored as well. Otherwise, the common fear is that it will lead to not very much change at all. Not surprisingly, condition charities believe they could make a greater impact on the Change Fund than they are currently able to. In its next phase, the Scottish Government could test out different partnership types across Scotland – the third sector and independent providers could take the lead in some places, with the onus upon the statutory sector to demonstrate what it can contribute. There are substantial variations in capacity, quality and innovation within each sector. Programmes like the Change Fund need to go where the expertise already is.

11. Improve the improvement cycle

Scotland has an elaborate network of scrutineers and regulators to promote improvement in public services. These span finance, quality standards and complaints. And yet, few believe progress towards consistently good experiences and outcomes is fast enough. It doesn’t look like ‘flogging the system’ harder, by increasing the volume of inspection for example, will get us there. Instead, other resources which can provide timely checks and balances are freely available but often neglected. These are the experiences of people who draw upon social care support, their carers and advocates. Our methods of hearing people’s views are partial and clunky. Can we safely assume that a postal survey conducted by a home-care provider generates an accurate picture of satisfaction and concerns? How do we get to hear the views of people with communication or sight impairments? Or those who are too fearful or too grateful for any kind of support to express their disappointment? A more powerful improvement cycle can emerge from the genuine involvement of people with long-term conditions, trained to take part in inspection visits and support peer groups, as well as a right to access advocacy and befriending support for frail and vulnerable people who lack good enough support networks of their own.

12. Collaborate across long-term conditions

The final proposition involves long-term condition charities seeing each other as partners in the culture change sketched out here:

• Better knowledge exchange: exploring support models following diagnosis is one example. What are the generic approaches to maintain everyday support
networks and functional capacity as long as possible, how far can they be applied and which are specific to certain conditions?

- **New groupings of related condition charities** might generate fresh insights, e.g. on communication impairment across conditions which is poorly understood by social care and falls between different branches of medicine (neurology, geriatrics, psychiatry); and common pathways through a condition might become a useful basis for collaboration (e.g. conditions which people can recover from; or are recurring; stable; degenerative; or terminal), crossing familiar boundaries between physical and mental conditions.

- **Making common cause in representations to government, donors and wider campaigns**: the Care and Support Alliance brings together more than 50 organisations with administrative support from Carers UK. It has managed to speak with an authoritative voice to successive governments, recently urging cross-party support for most of the Dilnot Commission’s recommendations. A similar grouping of environmental NGOs proved influential a decade earlier on the UK Government’s approach to climate change.

**Feedback**

LTCAS is committed to developing a programme on social care reform to better support people with long-term conditions. This discussion paper reflects only the first stage of activity. It is intended to stimulate argument – divergent ideas as well as consensus – to inform future stages.

Your comments are very welcome to:

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