LOCAL GOVERNMENT AND REGENERATION COMMITTEE

PUBLIC SECTOR REFORM AND LOCAL GOVERNMENT

SUBMISSION FROM EVIDENCE FROM LONG TERM CONDITIONS ALLIANCE SCOTLAND (LTCAS)

Key points

- The **third sector** – including small, grass-roots organisations and large national support and service providers – is a key delivery partner for local authorities.
- The approach to funding the third sector does not support full and effective partnership working or a sustainable shift to preventative, asset-based approaches. There is a need for local authorities and their partners to adopt a **strategic framework for funding the third sector locally**.
- The public service reform agenda and **Healthcare Quality Strategy** need to be more closely connected, the latter being the key driver for NHS Boards and staff.
- **Social care** is one of the most significant dimensions of public service reform but key challenges must be addressed, including:
    - Tensions between local autonomy versus equity in the quality of care and support across Scotland.
    - Ensuring support is based on human rights and independent living, not just meeting basic needs for survival.
    - Ensuring people with long term conditions are supported by health staff who recognise needs beyond the medical and social care staff who have sufficient understanding of the impact of long term conditions.

General Remarks

LTCAS welcomes the Committee's decision to undertake a year-long inquiry into public service reform. The two million people who live with long term conditions in Scotland are amongst those with the most to gain or lose as a result of how the public service reform agenda is implemented by Scottish Government, local authorities, NHS Boards and the third sector.

The Christie Commission offers a clear vision of the direction in which Scotland needs to travel. It sets out a path of transformational change based on integrated working, a shift to preventative approaches and asset-based models. The difficult question is *how* to achieve this change.

Association of Directors of Social Work (ADSW) has talked of the need for *"a new 'compact'… with the people who need support, both now and in the future".* At the heart of this is a move towards asset-based approaches in which the capacity, and voice, of individuals and communities is valued and maximised as a driving force for change.

Asset-based approaches such as self management, peer support and independent living must be at the heart of *how* we implement Christie. **However, LTCAS would highlight two distinct notes of caution based on the current experiences of our members and those they represent:**

- Such approaches must not translate, in reality, into an excuse to simply cut, rather than redesign, services, with the assumption that individuals, community groups and unpaid carers will take up the slack. The conceptual shift towards prevention remains ahead of the picture on the ground. Many services are being pared back to focus on crisis-level support, without accompanying investment in preventative, early stage interventions. There are a few positive developments beginning to emerge in relation to the Change Fund (referred to below), which should be encouraged, built upon and spread.

- While asset-based approaches offer high value for relatively low-cost, they do not come at no-cost. Third sector organisations – small and large – provide the foundation upon which asset-based approaches flourish. In reality many of these organisations are already being lost for the want of modest funding as local authorities and their partners pull back budgets.

Delivering on Christie requires a move away from the ad hoc approach to third sector funding, replaced by local strategic investment frameworks that support the sector as a core element of the care and support landscape.

Comments in relation to the Three Strands of the Inquiry

Better Partnerships with the Third Sector

LTCAS' public service reform conference identified a number of fundamental **barriers to the third sector participating as a full, equal partner** in the planning of services. These were:

- **Power** – there remains an imbalance of power underpinned by the relationship between the third sector and statutory partners as one of funder/funded. At a national level the relationship between LTCAS and the Scottish Government offers one alternative model in which funding is focused around a partnership agreement that is jointly developed and centred on shared outcomes.
- **Culture** – there is still a lack of understanding of the third sector, the scope of its activity and the impact and value for money it achieves. A few limited pieces of work have shown the benefits of increasing understanding and relationships between service planners/front line staff across the statutory and third sectors. LTCAS is currently working with the Scottish Government and others (under the auspices of the Healthcare Quality Strategy) to try to improve engagement and understanding between the third and statutory sectors.
- **Resources** – short term, uncertain funding continues to represent one of the most significant barriers to third sector organisations (a) participating as strategic partners and (b) delivering their potential impact. Staff in third sector organisations spend a substantial amount of time pursuing funding and reporting to (usually several) funding providers. Many, particularly small, organisations prove their value and yet exist on a 'hand-to-mouth' basis in relation to funding. This is often compounded by unrealistic expectations that third sector organisations or initiatives can become entirely self-sustaining, whereas they should be viewed as an ongoing investment in preventative, community-based, low cost activity. **A crucial part of delivering public service reform must be a rethink of how the third sector – including large organisations and grassroots groups – is funded in Scotland to enable a shift to a more intelligent, strategic and effective approach.**

There is important learning emerging from the Change Fund for Reshaping Care for Older People in relation to the third sector as strategic and delivery partner that should help to inform this discussion. Notwithstanding concerns about the effectiveness of engagement with the sector in some instances, there are interesting approaches developing including a 'Community Interventions Fund' in Fife and 'cash4communities' in Tayside. The question for both of these will be how successful community-led activities are sustained in the longer term.

Aligning Drivers behind Public Service Reform

In pursuing public service reform there is a need to more closely align the key drivers for health and local government. The *Healthcare Quality Strategy* and broader public service reform agenda, particularly *Self-Directed Support* share the same principles of: increased choice, control and capacity for individuals; co-production and asset-based approaches; and supporting independent living and quality of life, whilst seeking to prevent poor outcomes. Greater connection and shared

understanding across these agendas is essential to support partnership working across the health service and local authorities.

Harnessing Assets and Changing Culture

Scotland needs to move to a situation where preventative, asset-based approaches such as self management, personalisation, independent living, recovery and co-production are the rule, not the exception. The third sector is a key catalyst for making this shift, building on its track record of innovation and developing preventative, community-based approaches in which people's own capacity and voice is central.

The Self Management Fund for Scotland is one example that demonstrates that even a small investment in asset based approaches can produce a significant outcome in terms of quality of life for individuals, capacity building for people and communities, and reductions in the pressure on public services.

There appears to be growing appetite in Scotland for a more radical, wholesale move towards asset-based approaches. If this is to become a reality – and become a reality quickly – we need greater incentives for public services. NHS Boards, local authorities and individual practitioners must be expected to work with an asset-based ethos and statutory agencies need greater drives to invest in asset-based, preventative approaches. Performance management and benchmarking needs to support this shift, not work against it.

Outcomes

Services remain too focused on delivering their own separate service outcomes, rather than assessing success against the outcomes for individuals (who are likely to have been supported by a range of agencies from across sectors). This does not reflect the complexity of people's lives in which different aspects of need – for example housing, employment and health – are almost always closely inter-dependent.

Tackling embedded social issues and areas of multiple and complex need will require a more sophisticated – person-focussed, not service focussed – approach to identifying outcomes and assessing progress against them. **We need to be able to look at a person's journey through public services and measure success by whether the range and combination of support and services with which they interacted resulted in a positive outcome.**

This would also help to address the significant issue of what happens to people at the points where services connect (or should connect but don't). There is very welcome attention on health and social care for older people, but there remains a real need to also improve integration of services for others who are disabled and/or living with long term conditions, and very often also experiencing a range of related issues, for example around housing, finances or mental health.

Single Outcome Agreements should offer a mechanism to support a more effective, joined up approach. However they require further refinement to balance local

priorities with implementation of national policy, and to ensure effective involvement of all stakeholders.

Personalisation with a Purpose

The Committee asks *'What scope is there for developing ways of delivering services, such as the personalisation of care, in order to mitigate the effects of shrinking resources while also promoting improved standards of care?'* LTCAS would suggest that – while standards of care are clearly a vital part of the equation – the Committee should ask how personalisation can deliver, not just good quality care, but how can it fully support independent living, human rights and civic participation for people who are disabled or live with long term conditions. The framing of the discussion on public service reform matters in order that we guard against becoming focussed on delivery of services as an end in itself, rather than on the outcomes for the people they seek to benefit.

12 Propositions for Social Care

LTCAS, with partners, commissioned Dr Jim McCormick (Scotland Adviser to the Joseph Rowntree Foundation) to prepare a paper to stimulate dialogue on the future of social care for people with long term conditions. A broad range of individuals, organisations and evidence informed '*12 Propositions for Social Care'*, which maps key issues and puts these in terms of recommendations for a rights-based 'system for wellbeing'.

1. Recognise the context

- People living longer with long term conditions, and more living alone.
- Preventative spending – taking demand out of the system, not just due to public expenditure cuts, but also because this achieves better outcomes for people.
- Conceptual shift towards prevention is ahead of the reality of investment.
- Need for more flexible and responsive use of all care and support resources – need to *"reach for the volume control, not the on-off switch".*

2. Adapt to emerging needs

- Need to recognise the needs of children and young people and those of working age too.
- Emotional and psychological support needs for people with long term conditions and unpaid carers are significant.
- Loneliness can increasingly be considered as a long term condition – isolation and depression are 'below the radar' among the over 80s.
- There should be commissioning duties for mental health on long-stay NHS and care homes.

3. Start with rights

- More robust than dignity or respect.
- Range of related activity – Human Rights to Independent Living, application of United Nation's 'PANEL' approach to human rights for people with Dementia, Patient Rights and person-centredness focus within the NHS.

- Push for the right to self-assessment in community care.
- Need to address rights in the face of rationing effects for basic care.

"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****."*

4. Decide what kind of prevention we seek

- Public health, for example risks of high blood pressure/obesity for some types of stroke, diabetes and vascular dementia.
- Boost protective factors and build resilience, for example maintain social networks, exercise/activity, access to "bits of help".
- Delay use of high-cost care and avoid crisis for unpaid carers.
- Focus on secondary prevention, for example cutting risk of further heart disease or stroke, re-ablement support.

5. Use personalisation with a purpose

- To promote changes in culture, assumptions and behaviour around how needs are defined, support is sourced and how services engage with citizens (equal partners in care?).
- Individual Budgets/Direct Payments are one expression of self-directed support, but we need to understand the benefits and limitations.
- Community approaches to self management, for example peer support, have a significant role to play.

6. Balance generic and specific approaches

- Good generic approaches like person-centred planning apply to all long term conditions.
- Generic advocacy networks can engage with long term condition specialists to adapt their support.
- **But** social care needs to adapt to some of the common features of specific conditions, for example:
    - risk to personal safety (Alzheimer's)
    - unpredictable medication needs (Parkinson's)
    - undiagnosed depression (stroke)

7. Create a system for wellbeing

- Apply these elements of a better vision for social care consistently well – add a more sophisticated health care model addressing complex/multiple conditions.
- Combined, these can create a system for wellbeing – defined as *living well with long term conditions.*

- Independent living and empowerment can be regarded as *rights* through which we can live well, for example full civic involvement, not just 'keeping people in their homes'.

8. Use money for change

- Evaluations need to look at overall costs and savings as well as benefits in wellbeing, capability, satisfaction and feeling in control of daily life.
- Clear cost savings can be found across elements of a programme – total net savings may be small, but quality of life benefits much higher i.e. people stay well for longer.
- Costs and benefits need to be tracked for longer.
- Beware tighter competition for less money between levels of need (low-moderate vs. acute); condition types; and age groups… There is a feeling that "It's going to get rough out there".
- Bridging finance is needed to shift the balance of care so that it is easier to get 'step-up' social care and medical support in the community than to get a hospital bed.
- Broaden the lens to consider the full set of resources (money and people).

9. Involve people for change

- People with long term conditions, unpaid carers and their wider support networks can be engaged as peers and befrienders.
- Engage resources available through for example key workers, specialist advisers, co-ordinators and community nurses.
- Need to involve the social care and NHS workforce and personal assistants, and build their capacity around ethics, values and technical skills.
- There should be a community stake in social care, for example in Japan there is a 'care currency' in operation through timebank models.

10. Governance for change

- There is too much in the box marked 'local autonomy' which comes at a cost to individuals (for example the lack of portability of care/support packages).
- Accountability and scrutiny should be on a 'help and hassle' basis to improve the quality of care.
- Change Fund – needs tight focus on local match with national strategy, what works and the changes achieved.
- We need to grasp the question of care inequalities vs. legitimate variations in assessment, support and charging – are there minimum standards?

11. Improve the improvement cycle

- Support reflective practice on the frontline.
- Seek out unheard voices.
- Breach the 'gratitude barrier'.
- Involve advocates and befrienders as partners (and as whistle-blowers where appropriate).
- Use the complaints system pro-actively.
- All of the above should complement inspection and regulation.

12. Collaborate across long term conditions

- Related groups of long term conditions organisations can collaborate, for example on issues such as communication impairment which is poorly understood by social care and falls between conditions, neurology, geriatrics and psychiatry.
- Learn from each other, for example post-diagnostic support to maintain natural support networks, keyworkers/brokers.

Please read the full paper at
http://www.ltcas.org.uk/download/library/lib_4e71e74d61e59/

Concluding Remarks

As the Committee considers how local authorities can implement the public service reform agenda, it will be important to recognise that the economic climate is not the only driver.

The environment of rising need and falling public funds has helped to sharpen the focus on prevention and asset-based approaches, but these have been around for a long time in Scotland and reflect a growing desire from people to have a different relationship with support and services.

People do not want to be viewed as problems, or passive recipients of services. Nor do they want to make do with simply having their most basic needs met. They want to be treated as active citizens who contribute and enjoy the right to live high quality, independent lives in which *they* are in control. It is that energy and motivation that will provide the real driving force behind this agenda.

About LTCAS

The Long Term Conditions Alliance Scotland (LTCAS) brings together over 220 organisations that represent the two million people living with long term conditions in Scotland.

Find out more about asset-based approaches in ***Impact, an evaluation of the Self Management Fund for Scotland 2009-11*** and the *Assets Alliance Scotland Event Report* available on LTCAS' website.

www.ltcas.org.uk

The Long Term Conditions Alliance Scotland (LTCAS)
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