The Independent Living in Scotland Project, Strategic Advisory Group

Thank you for your letter of 20/03/2012 inviting written material concerning issues around the proposed health and social care integration, as seen by disabled people’s directly representative organisations in Scotland.

I am the Convenor of the Independent Living in Scotland Project, Strategic Advisory Group. Set up by the Scottish Government and working alongside both CoSLA and the NHS in Scotland, the Project has two main functions. First, to promote the ideas and practices of independent living throughout Scotland; and, second, to assist the Scottish Government to promote the principles and practices of independent living within mainline economic, health and social policy.

This project is now part of Inclusion Scotland which is an intermediary body of some 61 disabled people’s organisations throughout Scotland, with over 80 associated organisations and 500 individual members. Inclusion Scotland supports the principles of the Social Model of Disability. Its main aim is to draw attention to the physical, social, economic, cultural and attitudinal barriers that affect disabled people’s everyday lives and exclude us from participating in the mainstream of society.

Unfortunately, this Inquiry into the integration of health and social care has come at a time when the staff of both the Project and Inclusion Scotland are busy reorganising and moving premises, as well as trying to complete their business plans before the end of the financial year. It has, therefore, fallen on my less professional skills to lay before you our real concerns regarding this plan of integration.

First: some background & concerns:

1.1 More than 100,000 Scots of all ages receive social care and support including people who have a physical impairment; people with a learning disability; sensory impairment; mental health issue; autism; people with a range of long-term conditions; and those with dementia or who are elderly and infirm.

1.2 The Scottish Government has stated that – “Those who receive support should be at the heart of decision making about that support”. This is also in line with the recommendations of the Christie Commission that community participation should be embedded in the future design and delivery of public services.

1.3 Despite this none of the Health & Social Care Groups (i.e. Ministerial Strategic Group, Delivery Group, Integrated Resourcing & Budgeting, Joint Commissioning, Governance & Accountability, Locality Planning, the Bill Advisory Group, etc.) established by Scottish Government include any care service users whatsoever (though Carers and the Third Sector are represented ).
1.4 We believe that this is a serious omission and demonstrates a lack of linkage between the Scottish Government's stated intentions in relation to Self Directed Support and their plans for the integration of Health & Social Care services. For example the 2012-13 Change Plans include very little mention of Self Directed Support despite it forming a major part of the Government's legislative programme. We believe that the outcome of this health driven process will be void of the vital foundation of wellbeing, prevention and community involvement, which is so necessary to a sustainable, appropriate and valued system of health and social care

Second: the twelve propositions for valued and sustainable social care

2.1 These twelve propositions were arrived at through partnership work between sixteen organisations in the field of disability, research and policy development1.

2.2 The twelve propositions are – (1) Recognise the context (2) Adapt to emerging needs (3) Start with rights (4) Decide what kind of prevention we are seeking (5) Apply personalisation with a purpose (6) Balance generic and specific approaches (7) Create a system for wellbeing – not just better social care services (8) Use money for change (9) Involve people for change (10) Shape Governance for change (11) Improve the improvement cycle and (12) Collaborate across long term conditions. A PDF document of a two page flier is attached to this letter explaining each of these twelve propositions in greater detail.

2.3 Our key question on the planned integration of Health and Social Care services is - Will the integration result in better methods of prevention; more services to sustain health and wellbeing; greater personalisation of services; and improved opportunities of independent living for disabled people, as devised by disabled people themselves?

Third: Social Model or Medical Model?

3.1 Under the previously dominant medical model, disabled people are defined by their illness or medical condition. The medical model

---

1 Long Term Conditions Alliance Scotland; The Stroke Association (Scotland); Coalition of Care and Support Providers Scotland; Scottish Care; Voluntary Action Scotland; Joseph Rowntree Foundation (JRF); Self Directed Support Scotland (SDSS); National Osteoporosis Society; Thistle Foundation; Joint Improvement Team; Independent Living in Scotland; Neurological Alliance of Scotland; Alzheimer Scotland; Sense Scotland; Momentum and Parkinson's UK
promotes the view of a disabled person as dependent and needing to be cured or cared for. The disabled person is the problem, not society. Control resides firmly with professionals; choices for the individual are limited to the options provided and approved by the 'helping' expert.

3.2 The medical model is also sometimes known as the ‘individual model’ because it promotes the notion that it is the individual disabled person who must adapt to the way in which society is constructed and organised. The medical model is vigorously rejected by organisations of disabled people, but it still pervades many attitudes towards disabled people, particularly in the health field.

3.3 The social model of disability was developed by disabled people themselves in response to the medical model and the impact it has had on their lives. Under the social model, disability is caused by the society in which we live and is not the ‘fault’ of an individual disabled person, or an inevitable consequence of their limitations.

3.4 Disability is thus the product of the physical, organisational and attitudinal barriers present within society, which lead to discrimination. The removal of discrimination requires a change of approach and thinking in the way in which society is organised. The social model was developed with the aim of removing barriers so that disabled people have the same opportunity as everyone else to determine their own lifestyles.

3.5 The independent living movement in Scotland has invested a considerable amount of time and energy trying to move policies and services away from a medical model type approach to dealing with impairments to one based on the social model of disability. However we are concerned that the integration of health and social care services may see a return to the dominance of the medical model in terms of service planning and delivery.

Fourth: Integrated Services in Northern Ireland: A model to avoid?

4.1 The fear and concern about a return to the medical model of disability which is felt by Scottish organisations of disabled people is based on the experience of the integration of Health & Social Care services in Northern Ireland. This has been described as ‘one of the most structurally integrated and comprehensive models of health and personal social services in Europe’.

1
4.2 Further research by Heenan and Birrell in 2009 suggests that despite a number of achievements by the integrated service, there have also been a number of very significant limitations. **Of greatest concern to Scottish disabled people is that health dominates the agenda of the integrated service. The values and priorities of social care are subsumed by the dominant values and priorities of the health sector.**

4.3 The new integrated structures in Northern Ireland are large bodies whose membership is dominated by health professionals, rather than social care practitioners, or directly accountable politicians. This has led to a system of resource allocation whose primary concern is supporting the acute sector; with evidence of funding being diverted from social care to health with its higher public and media profile.

4.4 We note that this diversion of resources to acute care is completely at odds with the Scottish Government’s stated goal of supporting independent living by preventing illness and hospital admissions. Yet the Northern Irish experience suggests that *this will not be easily achieved without the needs and views of social care service users being given far greater weight than appears to be occurring within Scotland at present.*

4.5 Another concern identified by Heenan & Birrel is **the priority that the Northern Irish integrated service attaches to health agendas and targets**, for example there is a focus on the prevention and control of hospital infection rather than on preventing people being admitted to hospital in the first place.

4.6 Virtually absent from the Northern Irish experience of integration is **evidence of the progressive development of direct payments and individual budgets, of personalisation, and of children’s services.** Again this is at odds with the Scottish Government’s stated intentions. However, it does demonstrate how strategic thinking and service delivery within the Northern Irish integrated service has been dominated by the health agenda.

I should be most grateful if you could take these concerns to your committee to be given their deepest consideration.

Independent Living in Scotland Project Strategic Advisory Group

References:

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 proactively.
- 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.
- Make common cause on the right issue, for example as has been done by the UK Caring Choices Alliance.

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

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.