The Alliance, along with many of our members and partners, have called for five key points to be addressed to significantly strengthen the proposals and make the most of the opportunity they represent:

- A clear set of **guiding principles**, based on equality and human rights
- A **stronger voice** for those who use services and for unpaid carers
- A **strategic role for the third sector**, embedded in legislation
- A clearer fit with **self-directed support**
- Clarity on plans to extend integration to **other groups**

All of these points are expanded in the following response, and in the attached ‘Shared Statement from Third Sector Organisations’.

The Long Term Conditions Alliance Scotland (the Alliance) welcomes the Scottish Government’s commitment to integrating health and social care to improve outcomes for the people of Scotland. The third sector has long argued for – and delivered – integrated, high quality support that enables people to access their right to good health and independent living. Independent living includes people being able to remain at home, and not staying in hospital longer than they need to. However, if you ask people who use support and services they will tell you very clearly that it is about much more than that. **Independent living is about people’s whole lives and whether they have access to the same freedom, choice, dignity and control as other citizens, participating in society and enjoying an ordinary life**. Integration must not only be about getting people out of hospital, it should be about the kind of life the person has in their home or community.

The consultation document acknowledges that legislation is only part of what is needed to achieve integrated health and social care. However, the legislative basis for: a focus on shared outcomes;

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1Based on Independent Living in Scotland (ILIS) definition
joint accountability; integrated budgets; and locality planning, will undoubtedly form key elements of the foundations for this agenda.

While the legislation focuses on system-based changes, it needs to sit much more clearly within the context of the Christie Commission with its drive for prevention, equality and building individual and community capacity, all achieved through ambitious transformational change. This should be articulated in the legislation and its supporting materials and underpinned by a set of human rights based principles on the face of the bill.

Strategic commissioning of social care is complex and challenging due to reducing budgets, changing demographics, growing demands and expectations, and moves towards care more tailored to the individual’s needs. Despite this, councils and NHS boards need to do much more to improve how social care services are planned, procured and delivered through better engagement with users and providers and better analysis and use of information on needs, costs, quality of services and their impact on people’s quality of life.

Audit Scotland Commissioning Social Care (2012)

If integration is to succeed then strategic commissioning – and the involvement of service users, unpaid carers and the third sector within this – must be made more effective. The recent Audit Scotland Commissioning Social Care report made stark reading. It demonstrated a lack of effective commissioning processes or joint plans, insufficient investment in prevention, too little involvement of people who use services, or of the third sector, and a need for better use of evidence. What is perhaps most concerning is the lack of improvement in recent years and indeed several trends – including tightening eligibility criteria and increasing charges for the kinds of support that enables people to remain well and at home – that go against the drive for prevention.

The proposals for Health and Social Care Integration offer mechanisms for driving the improvement that has not happened to-date. However, there is a need for significantly more work to support local authorities and health boards to commission effectively, and in partnership, in the context of the constraints they face, and, crucially, for stronger and quicker action in response to lack of progress.

The Alliance looks forward to continuing to work with the Scottish Government, Scottish Parliament and others to drive this agenda and ensure the voice of people using services remains central. While there will inevitably be different views on the ‘how’ of health and social care integration, there should be strong political consensus on the need to drive this agenda forward. Indeed all
the main political parties featured some form of health and social care integration in their last Scottish Parliament manifestos. The Alliance hopes that all those involved in shaping and implementing these proposals nationally and locally will remain focused on the crucial aim of improving outcomes for the people of Scotland by ensuring we have a landscape of support and services that is high quality, effective and fit for the future.

This response has been informed by on-going, in-depth work with members and partners of the Alliance. This has been underway for almost two years and continues to develop dialogue and thinking on social care in Scotland. The group produced *12 Propositions for Social Care* (written by Dr Jim McCormick, Scotland Advisor to the Joseph Rowntree Foundation) and recently held a dialogue event with Scottish Government, NHS and local government leads for Health and Social Care Integration. The group also produced a *Shared Statement from Third Sector Organisations* to the Scottish Government’s proposals (included as an appendix to this response).

1. More than systems –a vision, supported by principles

1.1 Health and social care integration forms a major plank of public service reform. It offers a significant opportunity to do things differently and to ensure that systems and processes support – rather than inhibit – the approach envisaged by the Christie Commission. Despite the clear commitment of Scottish Ministers, expressed frequently in speeches and in evidence to the Health and Sport Committee, this bigger vision is not evident in the consultation document. The document, even in outlining its objectives (for example in the foreword), focuses on a morenarrow service-based perspective, often without reference to: driving a shift to prevention; significantly increased role for individual and community assets; and independent living.

1.2 There has been a strong argument – during the consultation process² and in the Health and Sport Committee’s short inquiry³

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² *Integration of Adult Health and Social Care in Scotland: Consultation, A Shared Statement from Third Sector Organisations* (published by the Alliance, July 2012)

³ Health and Sport Committee 5th Report, 2012 (Session 4)
– for a set of principles to underpin the legislation and guide its implementation. **A set of human rights based principles, on the face of the bill, and embedded within its provisions and related guidance**, would help frame the agenda and mitigate against a focus on systems, structures and processes as ends in themselves.

**The Alliance strongly urges:**

- A set of human rights based principles, including on the face of the bill and taken as the framework for guidance and implementation.
- A legal duty on Health and Social Care Partnerships (HSCPs) to have due regard to human rights.

Taking principles as a starting point would also help to broaden the focus of the integration agenda beyond statutory services. The vast majority of social care, and support for good health and wellbeing, is delivered not by statutory services but by individuals themselves, families, unpaid carers, peer and community-based support and the third sector. **Integration should be an important opportunity to improve connections between this type of support and statutory services, including in terms of strategic commissioning.**

1.3 The Alliance would also urge development of a vision for integration of health and social care that much more clearly reflects:

- The views, needs and capacity of people who use support and services.
- The full picture of health and social care, including the wealth of non-statutory support and services.
- Integration as a key plank of achieving the recommendations of the Christie Commission.

This would help frame integration in terms of its real purpose, rather than beginning from a service-based perspective. The need for this is reinforced by the consultation document’s setting out of the problems (paragraph 1.4) that integration needs to address; inconsistency in quality of care and support; delayed discharge; and avoidable admissions to hospital. While these are undoubtedly crucial issues that impact upon the lives of many people, there is a risk that integration is viewed through a service lens, rather than from the broader perspective of people’s lives. The need to re-focus efforts not just on people’s basic health needs, but
on their fuller quality of life is reinforced by recent evidence that while people are living longer, their quality of life into older age is worsening⁴.

1.4 Retaining a clear focus on independent living as the overall aim of health and social care is increasingly important in the face of UK welfare reform. This is a very real fear among many people that their ability to participate equally in society will be eroded as they lose access to support for independent living, and indeed this was echoed by the Westminster Joint Committee on Human Rights, which declared that "the government and other interested parties should immediately assess the need for, and feasibility of, legislation to establish independent living as a freestanding right".

2. **Stronger voice and role for people who use support and services and unpaid carers**

2.1 Despite the very welcome drive for 'asset-based approaches' within health and social care, the proposals reflect an increasingly outmoded view of services as 'doing to', rather than working with individuals and families, alongside the wealth of non-service-based support. The integration agenda needs to more strongly reflect the move for people – at individual and strategic level – to become active and equal partners alongside service providers.

The importance of people having a voice, being the lead partner in their own lives *and* helping to shape and deliver support and services is now a central tenant within Scottish policy. This is no less so when talking about older people. Indeed, as the Scottish Government, COSLA and NHSScotland recognise in *Reshaping Care for Older People, A Programme for Change 2011-2021*, older people should be viewed as valuable assets and provide far more care than they receive.

It is estimated that just over **3,000 people** over 65 years receive more than 20 hours of paid care per week, while over **40,000** people over 65 years provide more than 20 hours of unpaid care per week⁵. **Helping to support, sustain and grow this capacity, as well as that of friends and neighbours, is essential if we are to achieve better outcomes for more older people during a period of financial constraint.**

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⁴ Office for National Statistics
⁵ ISDScotland hospital discharge records (SMR01) (2008/09); GRO (Scotland) population estimates 2008
The voice, role and capacity of people who need health and social care support should be central to the integration agenda in a way that is not evident in the consultation document. For example paragraph 2.1 outlines the characteristics of a successfully integrated system of adult health and social care yet makes no mention of a successful system being one that works in partnership with people, families and non-statutory services and support.

Again, that people who use support and services will have a louder voice and greater choice and control is a notable omission in paragraph 2.8 where the document outlines what the proposals should mean for people in practice.

2.2 The proposals seek a greater role for clinicians and care professionals, however this needs to be in partnership with people who use services (for example in paragraph 2.3). This tone throughout the document adds to concern that the system will remain service-led and perhaps be dominated by a more traditionally medical-model approach, rather than empowering people to take control and bring their own capacity to bear.

2.3 Service user and carer representation on HSCP Committees must be as voting members. These representatives must be supported to be connected to a wider constituency and able to act as a conduit for people to influence strategic commissioning. People who use services and carers also have a vital contribution to make to scrutiny and improvement, supported by the third sector (including through Disabled People-led Organisations).

3. Bridging key divides across health and social care

3.1 Arguably the biggest barrier to making health and social care integration work will be the fundamental cultural difference created by the medical versus social model. In reality many health care practitioners look beyond people’s clinical needs and many social care professionals provide significant, expert support for people with particular conditions. However, this is still far from the norm and there remains a significant gap in approach with
clear differences between health and social care in terms of language, day-to-day practice, service design and planning, and investment priorities.

The Independent Living Movement in Scotland has expressed particular concern that the health model may be allowed to dominate in an integrated landscape. As well as impacting upon the day-to-day approach that people experience, this could result in commissioning strategies that do not sufficiently support investment in prevention, self management and independent living.

The scale and importance of the challenge created by the cultural is not adequately recognised in the consultation document.

3.3
While the cultural barriers are significant, the worst option would be to ignore them, or to miss the opportunity we now have to address them. The combined drive through integration, self-directed support and the emerging National Programme for Person-centred Health and Care (linked to the Healthcare Quality Strategy) – all within the broader Christie Commission agenda – offer a unique chance to fundamentally move Scotland to a position where policy and services are aligned around shared principles and work together to make a difference to people’s lives. This would be supported significantly by the inclusion of a set of human rights based principles on the face of the bill.

3.4
Another fundamental issue is how health services – universal and free at the point of delivery – and social care services – subject to eligibility criteria and charges – can be integrated. This relates to the point below about the need for far greater clarity on how integration and self-directed support will fit together in practice. A human rights approach, and the active involvement of people who use services, offers the best starting point for addressing this fairly and effectively.

4. Looking beyond the statutory sector – third sector as strategic partners

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6It’s our world too: The integration of health and social care (Independent Living Movement June 2012) available via www.ilis.co.uk
The third sector needs to be a key and equal strategic partner alongside the NHS and local government. This principle has been embedded within the Reshaping Care for Older People with the ‘three-way sign-off’ of local Change Plans. There is a risk that the proposals for integration, particularly the third sector as a non-voting member of the HSCP Committees, will represent a step back.

There is now consensus that health and social care services within Scottish communities need urgent attention. Knowledge of and ability to react to calls for change can be hampered by complicated communication pathways. As organisations frequently embedded within geographical and service user communities, third sector organisations are often free of this additional information filter... [and] have already moved to meet these demands and are making positive contributions to improving services.

There is an evidence base which demonstrates that volunteers are making a significant contribution towards services delivery in Scotland. Close ties between third sector organisations, communities and volunteers have facilitated the initiation and organisation of this informal service provision. Reviews of partnership engagement forums have demonstrated frustration amongst third sector organisations when confronted with a limited ability to influence real change. Moving forward with service reform could be assisted by better mutual knowledge and understanding of the evidence which demonstrates that the third sector can be a great benefit and of the evidence which discusses where and how partnership approaches work best.

The third sector is in some ways better equipped to overcome challenges facing public sector health and social care services. It is also important to note that many of the pressures facing the public sector are also affecting third sector. Calls for engagement need to be sensitive to the increasing draw upon resources and time that many organisations are facing.

Why Involve the Third Sector in Health and Social Care Delivery, Scottish Government and Scottish Third Sector Research Forum 2011

Integration of health and social care needs to begin with a much fuller view of the real landscape of support and services that operates across Scotland. The vast majority of health and social care support is delivered outside the statutory sector; by the third and private sectors, by communities, families, unpaid carers and
people themselves (for example through self management). The third sector provides the foundation that enables and develops much of this individual, family and community activity.

The sector also provides a third of formal social care services and consistently achieves high gradings in quality inspections compared to other sectors\(^7\). The Alliance would echo the view of the Coalition of Care and Support Providers in Scotland (CCPS) that this is due to ‘robust quality assurance systems, a strong commitment to user involvement and person-centred planning’\(^8\).

The Christie Report clearly articulates how crucial the third sector is to the future of public services, and the role it can play in helping to drive transformational change. The consultation document significantly overlooks the role, and potential role, of the sector to the integration agenda.

The consultation document describes ‘two key disconnects’ (paragraph 1.2) in our system; within health (between primary and secondary care) and between health and social care. However there are two more disconnects; between formal and informal support; and between statutory and non-statutory sectors. These also must be recognised and addressed if the needs of Scotland’s population are to be met effectively. There is a substantial risk that the integration agenda becomes centred on trying to improve partnership working between health boards and local authorities, rather than being truly about integrated health and social care.

The consultation document rightly states (paragraph 3.5) that success will depend on ‘a step change’ in the relationship between the NHS and Local Government. However, success will also require a step change in the relationship between those providing and those receiving services, and between statutory and non-statutory sectors.

4.3
The scale of change envisaged by Christie, and described increasingly by politicians, will not be achieved without the strategic influence of the third sector. The sector brings to bear

\(^7\)Figures published by the Care Commission have shown that the voluntary or third sector achieves higher proportions of ‘very good’ and ‘excellent’ gradings in a range of adult care and support services than its counterparts in the private or public sectors. (cited by the Coalition of Care and Support Providers in Scotland, CCPS)

\(^8\)CCPS response to Regulation of Care Inquiry 2011
significant resource, experience and insight. However, partnership must be on an equal basis, including within joint commissioning and locality planning, and as a voting member of the HSCP Committees. Without this the sector will not achieve the “influence [on] the spend of the totality of the resource” as described by the Deputy First Minister in evidence to the Health and Sport Committee. If commissioning (and therefore investment) plans are ultimately agreed only between the two statutory partners there is a significant risk that integrated budgets will be largely directed towards the same types of services, rather than on new, preventative and sustainable approaches.

The sector has two roles to play within commissioning and on HSCP Committees (something not recognised within the consultation document): supporting involvement of service users and carers, and as a strategic partner in its own right. There are issues for all sectors about how to ensure effective, genuine and accountable representation. However, the sector itself is well placed to develop a robust approach, building on the experience of involvement in the Reshaping Care for Older People Change Fund arrangements. The Change Fund: Enhancing the Role of the Third Sector Programme, housed within the Alliance, will be able to contribute to thinking on this.

The risks of allowing the third sector to be full and equal partners are far outweighed by the risks of adopting a more cautious approach in which the sector lacks real influence.

4.4
Work is already underway, under the auspices of the Healthcare Quality Strategy, to develop greater understanding and partnership across the third and statutory sectors. However, this should also be a key aspect of implementing integration. In particular, the ‘improvement and performance support’ for HSCPs (referred to at paragraph 4.19) should include capacity building for co-production and working with the third sector. This should be developed and delivered on a cross-sector basis. Understanding of, and capacity to work in partnership with, the third sector should be a key requirement of the role of the Jointly Accountable Officer.

4.5
The consultation document (paragraph 5.7) refers to the need for ‘robust, trustworthy information and evidence’ to inform planning and service design, joint management of risk, benchmarking across systems and accountability for delivery. This too needs to span across sectors and be supported through capacity building for people working across statutory, third and independent sectors.
5. A real shift in investment

5.1
The consultation suggests that Ministers will provide local HSCPs with direction on ‘the categories of spend to be included as a minimum’ in their integrated budgets. **This is a key opportunity to drive a real shift in investment, not just into non-institutional settings, but into preventative community-based support that helps people to stay well and enjoy an active, included, high quality life.** Much of this support is provided by the third sector (often at very low cost) and is already being reduced as local budgets tighten. This is at odds with the strategic intent consistently articulated by the Scottish Government to move towards preventative investment, supported by individual and community assets.

This is articulated in paragraph 5.3 of the consultation document, which acknowledges that ‘a shift in the balance of care requires a shift in patterns of resource allocation and utilisation, and that can only be achieved if the integrated budget includes the full range of spend on services’.

Given the evident gap between commitment to prevention and patterns of investment (for example evidenced in the Audit Scotland Social Care Commissioning report) it will be critical that Scottish Ministers and others scrutinise the extent to which this happens. Prevention may be implicit within the draft Health and Care Outcomes, however there needs to be analysis of whether the direction of travel specifically towards prevention and new patterns of investment and support are emerging (and whether at a fast enough rate).

6. An all-age approach

6.1
The initial focus on older people is understandable given the demographic challenges we face, and the urgent need to improve support for people as they go in and out of hospital. However, there are risks that:

- Integration will be designed for older people and then simply applied wholesale to other groups who may have different needs.
- In the immediate term there could be significant inequality among the many younger people who require both health and social care support and for whom lack of integration has just as detrimental an impact.
• The well versed problems that people experience at service-defined transition points (child to adult, adult to older person) will be worsened (and an opportunity missed to help address these).

6.2
As a minimum there is a need for some indication of the timescale and process for extending the drive for integration to other groups. The Alliance would also welcome further consideration of the Public Audit Committee’s recommendation that integration should include children and young people.

6.3
Health and social care needs to be based on a ‘life course’ approach, whereby investment in good health is made throughout life to maximise healthy life expectancy and prevent or delay onset of ill health where possible. This includes ensuring people with long term conditions are able to access the resources – including treatment and support – that enable them to manage their condition(s) and enjoy good health and quality of life.

6.4
Again, the issue of developing integration at different stages for different groups can be assisted through the development of a set of clear, core human rights based principles. While the needs of different groups will differ to some extent, core principles of this kind would be equally applicable and represent the guiding framework for health and social care for everyone.

7. A clearer fit with self-directed support

7.1
Significantly more dialogue is needed between people who use support and services, unpaid carers, policy makers and the statutory, third and independent sectors to examine how self-directed support will operate within an integrated landscape. The relevance of self-directed support to joint commissioning and locality planning is highlighted in the document (paragraph 7.1), however there is little further discussion.

7.2
Paragraph 5.2 of the consultation document describes the aim of creating ‘a system of health and social care in which resources – money and people’s time – can be used to best support the individual at the most appropriate point in the system – regardless of whether what is needed is “health” or “social care” support. The Alliance strongly welcomes this intention that resource will be
allowed to follow the person and lose its identity as either ‘health’ or ‘social care’ money. However, it is not clear how this would work in practice where someone wishes to direct their own support, including for people who want to use Direct Payments.

The proposals appear to suggest that all health and social care resource would be included in the ‘integrated budget’. This would suggest that people who received Direct Payments would receive them from this budget. However, at present they could only use the Direct Payment to fund ‘social care’ support.

7.3
Self-directed support will form an increasingly significant part of the full landscape of health and social care in Scotland and the Alliance would welcome the opportunity to contribute to the complex discussion of how this, and integration, can work well together.

8. Concluding comments

The Alliance broadly welcomes the significant structural changes being proposed. The replacing of Community Health Partnerships with HSCPs that sit across the NHS and local authorities is positive, as is the arrangements for joint accountability (although in practice the role of the Jointly Accountable Officer is likely to be a challenging one and the reporting mechanisms seem somewhat multi-layered).

The drive for integration must be viewed as part of the larger drive for transformation in public services. The Reshaping Care for Older People Change Fund provides an important platform but much more change is still needed. This requires a clear – and ambitious – vision and scrutiny of whether progress is being made, particularly in terms of effective joint strategic commissioning and changes in the pattern of resource investment to produce better outcomes. The Alliance supports the intention to provide a framework within which local areas will determine how outcomes will be achieved. However, it will be crucial that certain aspects of how this happens locally are required and local authorities and health boards held accountable, in particular:

- True, effective involvement of people who use services and carers.

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9 Note: the Alliance has recently established a new programme specifically to develop the connection between the self-directed support agenda/sector and the Healthcare Quality Strategy (particularly in relation to the new National Person-centred Health and Care Programme).
Strategic partnership with the third sector, including in strategic commissioning.

Requirement to deliver progress in shifting not just the balance of care from hospital to home, but in shifting the pattern of support, services and investment towards greater prevention, community and asset-based support.

Integration of health and social care should be placed within the wider Christie agenda and contribute to human rights and independent living; building capacity of individuals, families and communities; shifting to preventative investment; and developing a sustainable approach in the face of falling resources and rising need. Human rights, independent living and citizenship provides a framework for driving and connecting key agendas across health, social care and more widely, and as a basis for developing truly integrated policy, support and services nationally and locally.

The third sector has a long history of innovation and is driven by the voices of people who use support and services. If the sector is a key strategic partner in this agenda – nationally and locally – it can help to drive real change that improves the lives of people in Scotland. The sector is ready and willing to work alongside statutory partners to do this.

Health and Social Care Integration should not only be about trying to ‘fix problems’ within a system, it should be about ensuring people have the support they need to lead fulfilled, worthwhile lives.

For more information

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Please also find attached:

Integration of Adult Health and Social Care in Scotland, A Shared Statement from Third Sector Organisations (July 2012)

12 Propositions for Social Care (Dr Jim McCormick for The Alliance and partners, 2012)