

Consultation Response: Draft Regulations Relating to Public Bodies (Joint Working) (Scotland) Act 2014 – Set 1

31 July 2014

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. It brings together nearly 700 members, including a large network of national and local third sector organisations, associates in the statutory and private sectors and individuals.

The ALLIANCE welcomes the opportunity to respond to the draft regulations underpinning the Public Bodies (Joint Working) (Scotland) Act 2014 and the opportunity to build on the ALLIANCE's previous calls for evidence. Throughout this process, the ALLIANCE has held many wide ranging discussions with our members and others to establish our views on its impact for disabled people, people who live with long term conditions and unpaid carers.

The ALLIANCE continues to be concerned that the Act, and its draft regulations, does not strongly enough reflect the principles of human rights, including independent living. A human rights based approach would significantly contribute to ensuring the Public Bodies (Joint Working) (Scotland) Act improves outcomes for people, supported by better health and social care services in which they are active partners. The inclusion of rights-based wording within the principles contained within the legislation is however a very positive step, as are commitments that this will be reflected through the guidance. This response seeks to see such an approach further developed, particularly in relation to the Health and Wellbeing Outcomes.

Consultation Questions

1. Prescribed information to be included in the Integration Scheme

The ALLIANCE welcomes the information contained in the regulations outlining the key agreements that must be made between relevant public bodies to make integration a success. Broadly, we agree with the prescribed matters described in the regulations; however there are a number of areas where further consideration and clarification are required.

Participation and Engagement

The ALLIANCE believes that processes and procedures outlined as “prescribed information” must require each Health and Social Care Partnership not only to outline plans for involvement, participation and engagement of people who use support and services and unpaid carers but demonstrate how they have used such activity to shape their integration scheme and how it will shape strategy and future services. Demonstrating both “impact” and “outcome” of participation and involvement will add credibility to this process.

Communications

The ALLIANCE is concerned that the scope of the prescribed information focuses very strongly upon the technical nature of what should be done by integration authorities, rather than the wishes and requirements of people who use support and services, unpaid carers and others. The ALLIANCE believes that each integration authority should be required, through the integration scheme, to spell out its plans for clear, accessible communication with people who use support and services, unpaid carers and other relevant people about changing processes.

A key consideration must also be the flow and sharing of information across all partners, not just those in statutory bodies. This must include people who use support and services, the third sector and other representative groups.

The ALLIANCE is aware through informal sight of papers from emerging Health and Social Care Partnerships that some partnerships are so far focusing communications only towards statutory sector staff. This is at odds with the repeated reassurances from Scottish Government Ministers that integration will not be an exercise relating only to the statutory sector, but that it must be taken forward as a partnership including people who use support and services, unpaid carers and the third sector. Communications are key to supporting this approach.

Complaints

One example where communications must be strengthened is the emphasis placed on integration authorities to spell out the arrangements for the management of complaints. Whilst complaints are a welcome addition to the prescribed information required in each of the integration schemes, it remains unclear as to how people who use the service will know what the new process is.

Mechanisms should also be introduced to facilitate and enable ‘collective’ complaints from groups such as third sector organisations. NHS Boards have a duty to consult on service change, but social care often takes a more individualised approach, despite

many people experiencing provision in group settings, e.g. care homes. A collective approach would enable organisations to advocate on behalf of individuals who feel strongly that a particular service is not meeting their requirements and avoid the stigma of making an individual complaint.

If integration is to produce seamless services from the perspective of people using them, Health and Social Care Partnerships must be required to provide a clear, single route into complaints processes. This should also spell out a clear route for resolving them, communicating the decision to the person who made the complaint and taking responsibility for any follow-up action. This is one facet of ensuring the needs and experiences of people who use services can be listened to, learned from and help to drive improvement. Complaints processes are also a key accountability mechanism to enable people to access their rights in relation to health and social care.

Workforce Development Plans

Given the contribution of the third sector in service delivery, it is important that proposed workforce development plans consider the workforce in its entirety rather than simply statutory bodies. The third sector alone provides over a third of all registered social care services. We believe, therefore, that a reference to its role must be built into the prescribed information required from integration schemes and would want to see this explicitly within the guidance.

Alongside this there is also an increasing reliance on volunteers in service delivery, and many ALLIANCE members strongly rely on the efforts of volunteers and others. As issues related to volunteers are different from those related to the professional third sector workforce, a separate reference to their role should be explicitly included in the guidance.

Information Sharing

Integrated data collection and sharing has the potential to play a critically important role in supporting effective joint commissioning, strategic planning and service redesign at local levels. At present, information about people who use support and services is often held in multiple “silos” with inadequate mechanisms for the sharing of information between different professionals.

Our members have long expressed concern that this results in people having to repeat the same information every time they deal with a different professional and can lead to inconsistent information care and advice. The roll out of the Key Information Summary (KIS), an electronic health record containing key information about a person’s health records to be used in out of hours and emergency care, supports effective and person centred support for disabled people and people who have long term conditions. Such

methods of information sharing, provided choice is given to people who use support and services about what is shared, will be critical to ensuring a joined up approach.

The aims of the Health and Social Care Data Integration and Intelligence Project in developing a better understanding of the journeys of people who use services, particularly in terms of patterns of use, are welcome. However, despite the vast majority of health and social care support being 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 draft dataset (included in the recent Health and Social Care Data Integration and Intelligence Project consultation¹) does not include strong enough reference to third sector interventions and the wider individual and community assets that impact upon a person's health and wellbeing.

If the underpinning strategic and locality planning processes are to successfully reflect the need to shift to preventative solutions, they will require much greater evidence of the impact **of a range of solutions** upon meeting the outcomes of the local area and influencing 'flow' throughout the system. Integration schemes should require each authority to clarify how they will share information in a useful and responsible manner that meets the expectations of people who use support and services and seeks to improve outcomes.

2. Proposals for prescribed functions that must be delegated by local authorities

No comments.

3. Proposals for regulations prescribing functions that may or that must be delegated by a Health Board

The ALLIANCE would call for further clarification of the following terms:

- "Health visiting"

Clarification should be provided as to whether this should include health visits to both adults and children.

- "Women's health services – to include adult and child visits"

Clarification should be provided as to whether this also includes men's sexual health services.

¹ http://www.alliance-scotland.org.uk/download/library/lib_53bfa640da368/

4. Proposals for National Health and Wellbeing Outcomes

Do you agree with the prescribed National Health and Wellbeing Outcomes?

No.

The ALLIANCE welcomes the inclusion of National Health and Wellbeing Outcomes in the Public Bodies (Joint Working) (Scotland) Act 2014 as a means of improving quality and consistency and allowing for public scrutiny of the progress made towards health and social care integration. The outcomes are of critical importance to ensuring the agenda remains focused on the impact of integration on people, the required cultural shift and making sure that a greater emphasis is placed on a personal outcomes approach.

However, during a recent engagement event with ALLIANCE members, many delegates expressed concern that the outcomes reflect a 'maintenance' approach, rather than one that is about enabling people to live full and positive lives as contributing citizens.

It is important to be clear whether these outcomes will assess a journey of improvement, rather than absolute targets to be ticked off as 'complete'. If it is the latter, it would seem preferable to adopt sufficiently aspirational outcomes to drive the kind of change being sought. The ALLIANCE believes that the national health and wellbeing outcomes would be strengthened by adopting a human rights based approach. Use of rights-based language would reflect a more person-focused, aspirational set of outcomes, and its value can be seen in Scotland's work on dementia, in the Care about Rights programme² and in the work done within the State Hospital³. Our members believe that there would be benefit in refreshing the draft outcomes to make further reference to both the prevention and personalisation agendas.

We support the view of the Scottish Human Rights Commission that each of the proposed outcomes should reflect, and be grounded in, a human rights based approach in order to affect the transformational change as articulated by the Christie Commission⁴.

Below we have suggested a number of changes to the outcomes based on the views of ALLIANCE members and others.

² <http://www.scottishhumanrights.com/careaboutrights>

³ <http://www.scottishhumanrights.com/application/resources/documents/HRHCSFINALVERSION.pdf>

⁴ <http://www.scotland.gov.uk/Resource/Doc/352649/0118638.pdf>

Current Outcome 1: People are able to look after and improve their own health and wellbeing and live in good health for longer

Members of the ALLIANCE have expressed the need to ensure that the support element of this outcome is more explicitly spelt out. Self management, often supported by the third sector, remains centrally important within health and social care services and this should be further emphasised through this outcome and recognised in its associated indicators. Whilst we accept that this term may be difficult to legally define in this legislation, we believe that reference to support through accessible information and support should allow for this approach to be further emphasised. “Accessible information” is the general term used to describe making information easier to understand. The provision of accessible information should be a supportive process of simplifying language and conveying information and messages in different formats, appropriate to the needs and requirements of the person with whom you are trying to communicate.

Any underpinning definition of “wellbeing” in guidance in relation to this outcome should reflect not just a passive state of respect and comfort, but as the act of living an active participatory life. This includes having the rights and resources to participate meaningfully in life, including familial, social and civic activity, and should clearly include both mental and physical wellbeing.

Indicators related to this outcome should include measures of social capital. A recent Scottish Government report found evidence of a potential relationship between social capital assets and better health⁵. The report includes a number of indicators that we believe could be adopted to assess people’s level of social capital:

- Social networks and social support – how many people you could turn to for comfort and support; the level of contact people have with their relatives, friends and neighbours.
- Civic participation – how involved people feel in their local community; the extent to which people feel they can influence decisions in their local area.
- Reciprocity and trust – the level of trust they believe that they can put in people around them. This information is included in the Scottish Health Survey.

Proposed Amended Outcome 1: People are able to look after and improve their own health and wellbeing and live in good health for longer, supported by accessible information and support’

⁵ Scottish Government (2012) Social Capital and Health: Findings from The Scottish Health Survey and Scottish Social Attitudes Survey

Current Outcome 2: People, including those with disabilities, long term conditions, or who are frail, are able to live, as far as reasonably practicable, independently and at home or in a homely setting in their community

Members of the ALLIANCE have expressed the view that this outcome could also be strengthened by also including reference to end of life support for people living with a terminal illness.

Proposed Amended Outcome 2 – People are able to live as far as reasonably practicable, independently and at home or in homely setting in their community and to have access to effective end of life care at home

Current Outcome 3: People who use health and social care services have positive experiences of those services, and have their dignity respected

We believe that this outcome should have a greater focus on enabling people to exercise their rights. Human rights based approaches to health and social care can be a proactive tool for supporting people to do this. Having reference to human rights – rather than simply dignity – would give reference to a number of core principles, including dignity, but also including fairness, equality, respect and autonomy.

This outcome would be strengthened by inclusion of reference to participation of people who use health and social care services – included here under “have their views listened to and acted on”. The outcome refers to positive experiences but does not recognise the role of finding out what people want at an individual or collective level, to ensure this happens. There would be value in making clear that both people who use support and services and their unpaid carers should be involved in choosing the services they need, the way in which care is delivered and that both should be treated as partners in the decision making process.

Access to independent advocacy, both collective and one to one, would support people to have positive experiences of support and services. Collective advocacy groups can help to inform local community planning, needs assessment and the development of truly person centred health and social care services. One to one independent advocacy can ensure that all who need it can be supported to have their views listened to and acted on and their right to dignity respected.

If dignity is going to be used as a measure we should ensure that the “right to dignity” is referenced. This should not just be “respected” but actively enabled.

Amended Outcome 3 – People who use health and social care services have positive experiences of those services, have their views listened to and acted on and their right to dignity respected

Current Outcome 4: Health and social care services are centred on helping to maintain or improve the quality of life of service users

The ALLIANCE welcomes the emphasis placed on continuous improvement but would argue that the emphasis should be placed on supporting people to achieve their rights and support to live an independent life that includes contributing to their local community, and, where appropriate, participating in employment. This outcome should reflect an asset-based approach which seeks to enable and value the skills, knowledge, connections and potential of people who use support and services in contributing to the continuous improvement of health and social care support and services. Asset-based approaches recognise that people are not simply 'recipients of services' but that they also have a significant and critical contribution to make. In many cases this will require a change in individual and organisational attitudes values and practice in order to enable their voice to be heard.

The definition in this outcome should be brought into line with the Independent Living in Scotland (ILiS) project's definition of independent living⁶ which goes beyond the question of whether someone is able to live in their own home.

Independent living is a concept explicitly founded on human rights is enshrined in international human rights treaties to which the UK is legally committed and adopted by the Scottish Government in the Shared Vision for Independent Living. For many disabled people and people who live with long term conditions, practical assistance and support (such as access to the environment, advocacy, personal assistance, income, and equal opportunities for employment), underpinned by the principles of independent living, freedom, choice, dignity and control is essential for them to exercise their rights and duties of citizenship, via their full and equal participation in the civic and economic life of Scotland.

Amended Outcome 4 – Health and social care services respect the rights of individuals, are centred on helping to maintain or improve the quality of life of service users, and support them to contribute to their communities

Current Outcome 5: Health and social care services contribute to reducing health inequalities

The ALLIANCE welcomes the inclusion of an outcome which seeks to address health inequalities and also reflects human rights obligations under positive obligations of the right to life (Article 2 ECHR) and the right to health⁷. Health and social care services can play a contributory factor in reducing health inequalities; however this outcome

⁶ <http://www.ilis.co.uk/independent-living>

⁷ Ibid at footnote 6

must recognise the need to tackle the fundamental causes of health inequalities, including poverty and inequality of power⁸. Guidance should reflect a human rights based view of health inequalities which acknowledges that people have a right to health, and to the determinants of good health.

The Scottish Government should also measure the contribution of other key public service reforms to reducing health inequalities and how this complex issue is being addressed across service or policy silos. This could be supported by a Health Inequalities Impact Assessment, which is increasingly being promoted by NHS Health Scotland as an approach that brings together health inequalities, human rights and the public sector equality duty.

Amended Outcome 5 – Health and social care services contribute to preventing, reducing and undoing health inequalities

Current Outcome 6: People who provide unpaid care are supported to reduce the potential impact of their caring role on their own health and well-being

The outcome proposed for carers would be enhanced by expanding to include carers' ability to have a life outside of caring. ALLIANCE members felt that the draft outcome did not, at present, reflect the underlying principles of the Scottish Government's Carers Strategy and emerging rights-based approach to unpaid carers. The outcome does not reflect the fact that unpaid carers have a right to be listened to and respected (and that if that happens they require less support).

Amended Outcome 6 – People who provide unpaid care have their rights respected and are supported to reduce the potential negative impact that their caring role has on their health and wellbeing and enable them to maintain a life outside of caring

Current Outcome 7: People who use health and social care services are safe from harm

The ALLIANCE is concerned that this outcome, as currently drafted, could potentially undermine the need for risk enablement as well as harm reduction. Many ALLIANCE members feel strongly that there should be an outcome about people being safe from harm, reflecting the importance of issues such as infections (in hospital and care homes), elder abuse and harm to health caused by unnecessary time spent in hospital. However, this needs to be balanced to reflect the fact that people have a right to choice, control and personal autonomy and this can mean choosing to take risks. Risk enablement is a key part of agendas around personalisation, self

⁸ Equally Well, Ministerial Task Force on Health Inequalities, Review 2013, <http://www.scotland.gov.uk/Resource/0044/00446171.pdf>

management and independent living but is often undermined by risk-aversion within health and social care services – the outcome as it stands could worsen this.

Independent advocacy, can provide a safeguarding role, ensuring that people’s rights are upheld. Independent advocacy can support people to gather all relevant information, consider potential outcomes and make fully informed choices.

As such, we have proposed amendments to the outcome that further emphasise the importance of ensuring people are able to take full control over their life in a way that enables them to take risks and recognises the enabling principles of other legislation such as the Social Care (Self-Directed Support) (Scotland) Act 2013⁹.

Amended Outcome 7 – People who use health and social care services are safe from harm, are not overprotected and are supported to achieve personal autonomy and choice

Current Outcome 8: People who work in health and social care services are supported to continuously improve the information, support, care and treatment they provide and feel engaged with the work they do

The ALLIANCE believes that this outcome should focus on how people who work in health and social care services work directly with people to make sure that the information, support, care and treatment they provide recognises what people want from support and services.

People who access support and services and unpaid carers have an equally vital role to play in ongoing improvement but this is not currently reflected in the outcomes.

The ALLIANCE is concerned that rather than reflecting the Scottish Government’s significant focus on co-production and the increasing prevalence of asset-based approaches, this outcome maintains the ‘them and us’ distinction between paid professionals (as the main experts/source of information etc.) and people who use support and services (and the ‘needy’ recipients without expertise).

Amended Outcome 8 – People who work in health and social care services are supported to work in partnership to continuously improve the information, support, care and treatment they provide and feel engaged with the work they do; this must include working closely with service users and carers.

⁹ <http://www.legislation.gov.uk/asp/2013/1/section/1/enacted>

Outcome 9: Resources are used effectively in the provision of health and social care services, without waste

The policy aim behind this outcome explains the benefits for both individuals and services in targeting resources effectively; however the outcome itself focuses on whether resources are “wasted”, rather than a person-centred approach. It is important to recognise the importance of enabling people to stay out of acute care settings, because of the better outcome for their health and wellbeing and for the system, rather than only because it avoids “waste” in the system. We believe the reduction of waste is inherent in the ‘effective’ use of resources.

The background to this outcome should also be amended to emphasise the importance of the provision and availability of services which suitably reflect the needs and aspirations of people who use services. It should also recognise that independent advocacy, collective and one to one, can support partnership working between those delivering and those in receipt of health and social care services.

Additionally, the underlying indicators within Outcome 9 should reflect the drive for an asset based approach, and assess progress towards a situation in which all assets – including individuals and communities – are fully engaged in meeting health and social care requirements.

Amended Outcome 9 – Resources are used effectively in the provision of health and social care services to improve outcomes for people

Health and Wellbeing Outcomes Guidance

The guidance, due to be drafted and consulted upon in the coming months, must be clear and accessible for people who use support and services, unpaid carers and those involved in planning and delivering support and services. We support the approach suggested by the Scottish Human Rights Commission in its response that the guidance should explain what it means to take a human rights based approach, using the PANEL principles and the FAIR framework and how to apply them in practice. This would reflect the consistent reassurances given throughout the process of developing the Public Bodies Act that a human rights based approach would underpin integration. It would also reflect the Scottish Government’s commitment to the Scottish National Action Plan for Human Rights which identifies health and social care integration as a key priority for embedding a human rights based approach.

5. Interpretation of what is meant by the terms Health and Social Care Professionals

The ALLIANCE agrees with the prescribed bodies identified within the regulations and orders related to Health and Social Care Professionals. However, we believe this must recognise that many professionals work outside of the statutory sector.

Over a third of all registered social care services are provided by the third sector and the third sector workforce will play a critical role in achieving the final health and wellbeing outcomes. However, there still appears to be a lack of parity of esteem for third sector professionals and little understanding of their role. Regulations and guidance must be clearer in highlighting their role.

We agree with the response from Alzheimer Scotland that the definition of “Other Social Care Professionals who are not regulated by the Scottish Social Services Council but provide care or support to users of social care services” is vague and broad. This could include a personal assistant, with no health or social care training, who is employed by the person using services, either through Self-Directed Support or other means. Further clarity is required.

6. Prescribed functions conferred on a Local Authority Officer

These regulations state that only “Council Officers”, e.g. social workers registered with the Scottish Social Services Council (SSSC) or equivalent bodies; occupational therapists or nurses, can carry out investigations but they must have had 'at least 12 months experience of identifying, assessing and managing adults at risk'. We agree with the recommendation of Alzheimer Scotland that the regulations are amended to state that the relevant health and social care professionals must, in addition to the required experience, have completed specific training in assessing and investigating situations relating to adults at risk and carrying out such investigations.

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About the ALLIANCE

The ALLIANCE vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims; we seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.